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ABSTRACT

The Families as Allies Conference was held to promote collaborative working relationships between professionals and parents of seriously emotionally handicapped children and adolescents, at the case level as well as the service delivery system level. This working conference was designed to involve equal numbers of parents and professionals, including policy-making, administrative, and service delivery professionals from public systems and private service providers. Representatives from the following 13 states were invited to participate: Alaska, Arizona, California, Colorado, Hawaii, Idaho, Montana, Nevada, New Mexico, Oregon, Utah, Washington, and Wyoming. Included are transcriptions of speeches and panel presentations, a biographical sketch of each speaker, participant worksheets, and conference evaluation responses. Susan DeConcini gave a keynote address titled "Respect: The Key to Successful Parent-Professional Collaboration." Panel presentations dealt with obstacles to parent-professional collaboration and overcoming those barriers by viewing parents as allies of the professionals. Action plans composed of goals, strategies, and obstacles are included for each of the 12 participating states. (JDD)

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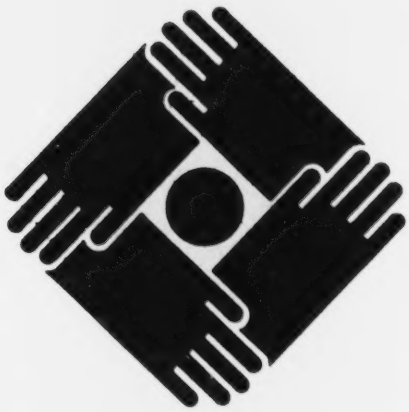
FAMILIES AS ALLIES

Conference Proceedings

Parent-Professional Collaboration
Toward Improving Services for
Seriously Emotionally Handicapped
Children and Their Families

April 28-29, 1986
Portland, Oregon



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and
CASSP Technical Assistance Center,
Georgetown University Child Development Center

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FAMILIES AS ALLIES

Conference Proceedings

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INTRODUCTION

The Families as Allies Conference was held in Portland, Oregon on April 28 and 29, 1986. The mission of the conference was to promote collaborative working relationships between professionals and parents of seriously emotionally handicapped children and adolescents.

CONFERENCE OBJECTIVES

The primary objectives of the Families as Allies Conference were: (1) to develop a base of knowledge and experience for professional/family efforts to advocate for the needs of seriously emotionally handicapped children and youth; (2) to stimulate activity within individual states aimed at increasing the extent to which professionals and family members work together to improve services to seriously emotionally handicapped children; and (3) to develop and disseminate work products of the conference which will be useful in ongoing work regarding parent-professional collaboration.

The conference was designed to promote collaboration between parents and professionals at the case level as well as at the service delivery system level. The format of the conference was designed to provide opportunities for participants to identify issues and barriers related to parents and professionals working together at both the case and systems levels, for parents from different states to meet together and share experiences, for professionals to meet together and for state parent-professional delegations to develop plans and strategies for implementing ideas in their respective states or local communities so that the needs of emotionally handicapped children and their families may be better met.

PARTICIPANTS

This working conference was designed to involve equal numbers of parents and professionals from thirteen western states. Representatives from the following states were invited to participate: Alaska, Arizona, California, Colorado, Hawaii, Idaho, Montana, Nevada, New Mexico, Oregon, Utah, Washington and Wyoming.

While the composition of each state delegation varied, our goal was to assemble state delgations which would be composed of: (1) policy-making, administrative and service delivery professionals from the major public systems that serve emotionally handicapped children and youth, i.e., mental health, child welfare, juvenile justice, education and vocational rehabilitation; (2) private service providers; and (3) parents of emotionally handicapped children and adolescents. Each delegation was encouraged to meet prior to the conference.

We relied upon the assistance of each state's SMHRCY (State Mental Health Representative for Children and Youth) representative in our efforts to assemble the thirteen state delegations. SMHRCY representatives served as coordinators for some state delegations. In other states Research and Training Center staff assumed responsibility for organizing the delegations, or other professionals were identified who agreed to serve as state coordinators.

Within each state, SMHRCY representatives and other state level professionals assisted us in identifying professionals and parents who would benefit from participating in the conference. Potential parent participants were also identified by organizations located through a national survey of parent organizations.

In order to insure the broadest possible participation, parent scholarships were offered which covered travel, lodging and meals. Additionally, financial assistance was provided to a limited number of professionals who wanted to attend the conference but who were unable to obtain funding from their agencies. We also assisted interested parents and professionals in locating alternative potential funding sources within their own states.

In addition to the thirteen state delegations, conference participants included speakers, panel members and workshop leaders with experience and expertise in the area and specially invited representatives of organizations concerned with improving services to families of children with serious emotional handicaps. Approximately 170 people participated in the two day meeting, including Research and Training Center staff and others who provided assistance such as serving as group facilitators and recorders.

SPONSORSHIP

The conference was sponsored by the Research and Training Center to Improve Services for Seriously Emotionally Handicapped Children and Their Families at Portland State University in Portland, Oregon and by the CASSP Technical Assistance Center at the Georgetown University Child Center in Washington, D.C.

The Research and Training Center was established October 1, 1984, through funding by the National Institute for Handicapped Research (NIHR) in collaboration with the National Institute for Mental Health (NIMH). A major effort of the Center is the Families as Allies Project which conducts research and develops training materials and experiences to promote more productive working relationships between professionals and families of children and youth with emotional handicaps. The Families as Allies Conference is a natural outgrowth of the Center's work in this area. The Research and Training Center is affiliated with the Regional Research Institute for Human Services, Graduate School of Social Work, Portland State University.

The National Institute of Mental Health (NIMH) recently launched the Child and Adolescent Service System Program (CASSP) to address the needs of severely emotionally disturbed children and adolescents. The program is designed to assist states and communities to improve systems of care for this population. In accordance with this goal, NIMH established the CASSP Technical Assistance Center at Georgetown University to offer consultation to the field and to assist in knowledge development and dissemination.

CONFERENCE PROCEEDINGS

These conference proceedings include: (1) the conference agenda; (2) edited transcriptions of speeches and panel presentations as well as a biographical sketch of each speaker; (3) specific state recommendations and action plans; (4) participant worksheets; and (5) conference evaluation responses.

We hope that the conference experience will be the impetus for further activity and development in participating states in the months following the conference. We believe the conference proceedings will be useful to groups and communities interested in increasing the extent to which parents and professionals can work together on behalf of emotionally handicapped children and adolescents. Additionally, the conference design may be adaptable to other needs and circumstances.

We extend our sincere appreciation to all conference participants. Their contributions will help translate the concept of "Families as Allies" into reality.

FAMILIES AS ALLIES: PARENT-PROFESSIONAL COLLABORATION TOWARD IMPROVING SERVICES FOR SERIOUSLY EMOTIONALLY HANDICAPPED CHILDREN AND THEIR FAMILIES

April 28 and 29, 1986
Portland, Oregon

Monday, April 28, 1986

8:00 a.m. Conference Registration

9:00 a.m. Greetings and Presentation of Conference Format

9:30 a.m. Keynote Address: **Respect: The Key to Successful Parent-Professional Collaboration.**
Susan DeConcini, MSW

10:00 a.m. Beverage Break

10:15 a.m. Panel: **Obstacles to Parent-Professional Collaboration**
Moderator: Thomas Young

Cindy Boatman	*Topeka, Kansas*
Richard Donner	*University of Kansas*
John Morgan	*Division of Community Rehabilitation, State of Idaho*
Glenda Fine	*Mental Health Association of Southeastern Pennsylvania*
Anthony Zipple	*Research and Training Center, Boston University*

12:00 noon Luncheon Speaker: Laurie Flynn, *Executive Director National Alliance for the Mentally Ill*

1:30 p.m. **Small Group** deliberations to identify obstacles to parent-professional collaboration. All groups will meet on the ninth floor of the conference hotel.

Parents and professionals will meet separately for the first 45 minutes. Then professional and parent sub-groups will join.

Recorders will summarize activities of the small groups for presentation to the full conference on Tuesday morning.

3:00 p.m. Feedback Session

3:30 p.m. Beverage Break

4:00 p.m. **WORKSHOPS**

A. ORGANIZING PARENT SELF-HELP GROUPS

Cindy Boatman	Topeka, Kansas
Richard Donner	University of Kansas
Glenda Fine	Mental Health Association of Southeastern Pennsylvania
Linda Scharnberger	Child Advocacy Project, Alliance for the Mentally Ill of Wisconsin, Inc.

WORKSHOPS, CONTINUED

B. **WORKING WITH ETHNIC AND CULTURAL MINORITY FAMILIES**

Sam Chan — Multicultural Training Project, Los Angeles

C. **PROMOTING PARENT-PROFESSIONAL COLLABORATION: THE FEDERAL ROLE**

Judith Katz-Leavy — National Institute of Mental Health
Fran Vandivier — Temple University

D. **FROM CHILDHOOD TO ADULTHOOD: TRANSITION ISSUES**

Matthew Modrcin — Youth in Transition Project
Richard Engstrom — Research and Training Center, Portland, Oregon

E. **DEVELOPING COOPERATIVE RELATIONSHIPS: ISSUES AND STRATEGIES**

Anthony Zipple — Research and Training Center, Boston University

5:30 p.m.-6:30 **No Host Cocktail Hour**

Materials related to the conference theme will be displayed in the foyer. A video-tape presentation will be shown in the Crater Lake Room adjacent to the foyer at 6 p.m.

==========

Tuesday, April 29, 1986

9:00 a.m. Presentation of group deliberations.

9:30 a.m. Panel: **Overcoming Barriers to Parent-Professional Collaboration**
Moderator: Phyllis Magrab

Sam Chan — *Multicultural Training Project, Los Angeles*
Dagmar Plenk — *Wisconsin CASSP Coordinator*
Linda Scharnberger — *Child Advocacy Project, Alliance for the Mentally Ill of Wisconsin, Inc.*
Marsha Gould — *Colorado Children's Campaign*

10:30 a.m. Beverage Break

10:45 a.m. **Small groups organized by state delegations** meet to begin their planning process. All groups meet on the ninth floor.

12:00 noon Lunch: State delegations will sit together.

1:30 p.m. Parents and professionals **continue meeting in state work groups** to develop action plans and strategies.

2:45 p.m. Beverage Break

3:00 p.m. - 4:30 p.m. Plenary Session: **Presentation of state action plans and strategies**

INTRODUCTORY REMARKS

MARY HOYT

Mary Hoyt has been Director of the Child and Adolescent Training Program at Oregon State Hospital since November, 1985. Prior to that she worked at the Oregon Mental Health Division for 11 years and was responsible for planning and developing mental health services for children and adolescents. Ms. Hoyt has been a member and president of the State Mental Health Representatives for Children and Youth (a national organization) and was involved in the initial stages of the planning and development of the CASSP initiative.

Thank you. This is great. I am seeing people that I haven't seen for three or four or five or six months from all over the country. It's just super--I love it. Joe Murray, the Administrator of the Mental Health Division was not able to be here today and I am bringing his greetings and best wishes for a good conference. I also want to express my appreciation to the Portland State Research and Training Center. This is a marvelous occasion to bring people together from 13 states and again to Phyllis, because the CASSP Technical Assistance Center is also funding this conference.

I was thinking on the way up this morning that we have two days to really look and delve into a topic that I think we should have been working on for years and years. It's really how do we as helpers work with parents of severely emotionally disturbed children? I think we have some challenges really laid out for us. The primary one is to be very open and honest about our feelings. Our feelings as parents, because oftentimes I've heard from parents, "Yes, they always thought it was my fault my child had this problem." And that's always been a barrier, I think, for parents. Then, I think, on the helpers' side, therapists' side, I've heard, "Well, the parents can't really understand that kind of complex dynamics of all the things that are going on." That sets up a barrier. I think that, as we sit together, we have to be open with each other and get those things out on the table.

I think the other challenge is to listen to each person as they speak and try to identify at the feeling level what they have been through in working with an emotionally disturbed child. Sometimes the frustration of the helper is very evident when a parent gets into therapy. We don't have all the answers and to say we do is foolhardy and, I think, sometimes we have to admit that we are as frustrated as the parent.

As we look at these two challenges, then the next challenge is to kind of reach out to see where we can build those bridges and then join hands to look at how we can become solid partners to really address the needs of the emotionally disturbed child. I look at this as kind of a first step of where we're going and I look at the potential for the advocacy for the group of children that I think have been neglected throughout the years. And I also look with some envy at the Association for Retarded Children and the strong advocacy that they've been able to build through the years. And most recently, through the Alliance for the Mentally Ill, and how effective they have been for the mentally ill. So I'm looking at the two days with a lot of hope and I think we have a lot of potential here in this room. I wish us all well the next two days--my personal greetings, and also from the Division.

On a separate note, how many people here are Portland people? Now all of you pay attention to this. Try to hook up, for the people from out of state, with

someone from Portland so you can find out the fun places to go and have good dinners and enjoy yourselves. I hope that some of you can stay over a day or two longer, because Oregon's a beautiful state and we're proud of it and hope you enjoy yourselves. Oh, we will have sunshine, you'll see it in and out of the clouds and it will be great. Welcome to Oregon for you who have not been here before and welcome to Portland and I'm looking forward to a great conference.

ARTHUR C. EMLEN

Arthur Emlen is Director of the Regional Research Institute for Human Services (RRI) and a Professor in the School of Social Work. Dr. Emlen received his Ph.D. from Tulane University and was a postdoctoral fellow at the University of California, Berkeley. He has been on the faculty of the School of Social Work since 1965.

Dr. Emlen has been director of the RRI since 1973. The Institute, with which the Research and Training Center is affiliated, conducts research in a broad range of human services. Its fields of research include child welfare, child care, employment, vocational rehabilitation, mental health, and the family. The RRI has devoted much of its research to methods of supporting family strengths and to developing informal networks or other human resources for self help, mutual aid, helping, provision of care, and independent living.

I want to welcome all of you on behalf of Portland State University. I'm sure I also speak for our co-sponsors, Judith Katz-Leavy and Phyllis Magrab, as well as for Naomi Karp of the National Institute of Handicapped Research, who I know would have liked to have been here if she could have traveled.

It is an honor to be hosting such a timely and important conference. I'm told that parents and professionals are about in equal number here and that this assures that this will be a working conference, focused on the communication between the two groups and what they have to say to each other. I know that this conference expresses the philosophy of the Research and Training Center and, in particular, the Families as Allies project.

I hope that the work that will occur here will be important to you back in your states and that you're going to start something that will be of significance nationally.

The importance of what you're about to do came home to me personally recently. In the last week a friend of mine held a memorial service for her son, a son who was in my son's class in high school. He took his life after some years of torment, feeling alone and afraid. He was a talented lad, but he said the day before he disappeared, "I'm taking charge." And he did take charge of his life the only way he knew.

He didn't know about this conference, but there's a message in it for us. The only way in which families can take charge and professionals can take charge is by working together. They need each other. The communication that will take place here will be a major contribution to that cause. Thank you.

KEYNOTE ADDRESS

SUSAN DECONCINI

Ms. DeConcinci is a child care advocate. Her interest in children's issues is reflected in the organizations and activities with which she is associated. These include:

o Congressional Families for Drug Free Youth (Treasurer)

o Chairperson of the Advisory Committee of the U.S. Senate Child Care Center

o "Let's Talk," a project related to teen pregnancy (Phoenix, AZ).

o Intergenerational child care center in Phoenix called "Young Company" - (co-chairs fund raising).

o Honorary chair of the fund drive of the Comstock Children's Foundation in Tucson, AZ.

o Arizona state advisory committee for Parents Anonymous.

Ms. DeConcini is a practicing social worker in the mental health field. As the wife of Senator Dennis DeConcini of Arizona, she currently lives in the Washington, D.C. area and commutes to her home in Arizona.

All of us are here to explore ways that can enrich the communication between the parents of an emotionally handicapped child and the professionals who treat that child. It is my experience that families and professionals oftentimes are worlds apart. Perhaps that is your experience too. We are here today to try to build bridges between them.

Pearl Buck, the only American woman of letters to win the Nobel Prize for Literature, was the mother of a retarded child. She talks with great feeling about that experience in her book, "The Child Who Never Grew":

> Parents may find comfort, I say, in knowing that their children are not useless, but that their lives, limited as they are, are of great potential value to the human race. We learn as much from illness as from health, from handicap as from advantage--and indeed perhaps more. Not out of fullness has the human soul always reached its highest, but often out of deprivation. This is not to say that sorrow is better than happiness, illness than health, poverty than richness. Had I been given the choice, I would have a thousand times over chosen to have had my child sound and whole, a normal woman today, living a woman's life. I miss eternally the woman she cannot be.

The parent of an emotionally handicapped child knows what incredible change there can be in his or her life. That parent knows major stress. That parent knows tremendous demands on his time and energy. And there are situations where there seems no end in sight. The parent of one retarded child compared herself to mothers whose children are recovering from short-term illnesses. She

described those mothers as getting reprieves from life's daily expectations. Their husbands will shop for groceries, she said. A friend can drive in the car pool that week, the dentist appointment can be postponed, the piano lesson cancelled, back-to-school night skipped. But this she underscores in red: "There is nothing temporary about the catastrophic demands of time and energy made by a retarded child, and one cannot expect friends and family to respond endlessly to a crisis which is chronic."

Unfortunately, in many cases, the impact of an emotionally handicapped child can deal a devastating blow to a parent's self esteem. One mother of a handicapped child put it this way: it's a daily struggle not to admit that "having a disabled child makes us disabled persons." She described watching a young woman in a shoe store as her handicapped daughter marched up and down the racks, humming, clapping her hands, and talking to her image in the mirror. It was as if that mother's entire focus was on the image she presented to the outside world:

> Every bone, muscle, and nerve in the mother's body was concentrated on the task of appearing composed, at ease, unembarrassed. Somehow it seemed that just being the child's mother was not enough, not the major task. What was more important was the role of "well-adjusted parent," of conveying the message to an ever-observing public that she was managing, she was doing well; it was not getting her down. Yet the tension in her pose, the studied casualness with which she noted the youngster's activity--constantly keeping an eye on the possibility of shoe boxes becoming overturned, while she earnestly engaged the clerk in discussion of various styles--presented a picture of someone very hard at work in service to a relentless awareness.

Yes, the change emotional illness brings to a family is incredible. Mary Akerley, a former teacher and a mother of an autistic child, describes this change as it relates to the way parents regard the professional they go to for help. "We don't begin in anger. We start out the way all parents of all children do: with respect, reverence really, for the professional and his skills. The pediatrician, the teacher, the writer of books and articles on child development, they are the sources of wisdom from which we must draw in order to be good parents. We believe, we consult, we do as we are told, and all goes well unless . . . one of our kids has a handicap."

Imagine these parents who have great reason to believe their child has a serious emotional handicap. They are operating under a great fear. Often they come to professionals vulnerable, defensive, already guilty and ashamed. They are coming for help. Sadly the evidence we have shows that the parent-professional relationship which forms may not be an easy one.

There are many reasons. Parents' defensiveness, depression, guilt, shame, loss of self-esteem can all sabotage the partnership. A professional can disrupt the partnership whenever he or she falls prey to the myth that professionals, purely and simply, know everything. Credentials and fancy titles aside, there are times that professionals really do not know what to do. The trick then is to say "I don't know." The danger here is the professional's desire to be precise. And let us never underestimate this danger. In this desire to be precise, professionals can overlook the need to be supportive.

Professionals can sabotage the partnership whenever they cast the parents as villains--whenever they blame the way Mrs. Roberts brought up Mary for Mary's schizophrenia. Professionals can sabotage the partnership whenever they allow their ego to charge between a child and his parents in an effort to make themselves first in that child's life. It may seem strange that parents and professionals may interact competitively, but each may feel threatened if he believes he has failed where the other has succeeded.

Let me quote once again Mary Akerley, whose child, you remember, is autistic. She describes with great feeling her child's therapist and his killer competitive drive that destroyed any chance for a constructive partnership:

> I remember when Eddie learned to kiss. We had taught him the mechanics and had been getting back a lifeless touching of his lips to our cheeks. Then one night at bedtime it happened--a real kiss. I could hardly wait to report this exciting mark of progress to Doctor Number Two. At our regular session a few days later, he pre-empted me (he had seen Eddie the day before).
>
> "Eddie kissed me," he announced smugly with the most self-satisfied look I have ever seen on a human face.
>
> "Me, too" was all I could say.
>
> "When?" There was actually fear in his voice and when he heard the answer, he was visibly upset. "That means he kissed you before he kissed me."
>
> "Right, doctor," Mary thought to herself, "and that is as it should be."

And so the walls go up where bridges should be built.

I read a book that had a great impact on me. That book is "Parents Speak Out: Growing with a Handicapped Child." It's written from a very special perspective--and that perspective is all-important. It's written by professionals who are also parents of a handicapped child. Invariably, in each case professional detachment breaks down. The emotion of a parent takes over. The positive news is that these parent-professionals--because of their particular situation--arrive at an insight about their own past professional shortcomings. They pass this insight on to us.

Ann Turnbull is on the faculty of the Division of Special Education at the University of North Carolina. She is married to a lawyer who specializes in mental retardation law. He also happens to be the father of a mentally retarded son by his first marriage. It's important to know that Ann Turnbull--with three degrees in special education and numerous books and articles to her credit--was a professional in the field of mental retardation before she married her husband and before she became a mother to Jay.

Ann talks about one day in her life when she sat in an observation room and watched Jay take test after test. She talks about her own change in perspective. "I was shocked," she said, "at how different it was to observe as a mother rather than as a special educator." She describes her reaction to the

college students who were observing Jay in the same room she was in. "They were making remarks about Jay's language and motor skills and pointing out his particular deficiencies," she said. She describes her growing anger at how casually they made their comments.

She then describes her feelings at discovering these students had read Jay's records. Ann Turnbull, the professional, knows it's standard practice for students to have access to these files. Ann Turnbull, the parent, is incensed that Jay's past and their family business "had been invaded by sheer strangers." Finally she sits down with colleagues she knew were sensitive, supportive, and helpful. But as she sat there receiving the information about Jay, it was a struggle, she said, to remain composed and in control. "I wondered how many parents had left a conference with me in my role as special educator and experienced the same reaction . . . That's what really hurt. I felt both parental anger and sorrow over some of my own professional mistakes in previous interactions with parents."

What Ann Turnbull and Philip Roos and other professionals in this book who also happen to be parents of handicapped children give us is the gift of their own special perspective. They underscore that parents of emotionally handicapped children are desperately seeking knowledge about mental illness and the skill to cope with it. Communication between parent and professional is, therefore, essential. So is a professional's skill in listening. Ann Turnbull talks about a psychologist listening carefully to Ann's concerns about Jay. While she listened, tears came down her cheeks. Ann said the silence was beautiful. "It confirmed she was hearing what I was saying and sharing my feelings."

These parent-professionals let us know how important sharing is--not just sharing feelings and thoughts, but sharing experiences. Now, instead of assigning term papers to her students, Ann Turnbull requires them to build a relationship with a handicapped child. The relationship is to be like a friendship, with both sharing activities together such as shopping, cooking, riding public transportation and listening to music. They can all talk about the respect for the child as the essential bond between parent and the professional. And respect, in my opinion, really means equality. There's no other more apropos word to describe it. Equality means that you value other people as you do yourself. One mother of an emotionally handicapped youngster shared this story.

> When I was in graduate school I happened to be sitting in the coffee shop with a friend when a young woman stopped by the table. A friend of my companion, she had just graduated in special education. When she was asked what she would be doing next fall, she replied that she would be teaching a "bunch of nuts over at the Fifth Avenue School." My son was one of those nuts. It was not a good year for him in that school. His teacher had no respect for him and she expected very little from her students and got exactly that. How could I respect her? But by contrast, and more often the case than not, my son had one teacher who expected him to learn. She was hard on him. He had homework; he had to learn part of a class play. He had responsibilities. He also had an entry in the community science fair. He won a statewide art contest and discovered, <u>discovered</u> that he could read.

This teacher in one year accomplished more with my son
than the accumulation of the other years altogether.

Now some of the bad news stories that I've relayed from these books are not representative of the whole. But I think if you're going to have two days of productive discussion sometimes you have to get the negatives out first and then you can work back through what is causing them and how to avoid those sort of situations in the parent-professional relationship. The key is this respect--professional for child, parent for professional. It really is a partnership--a joining of hands together so that everybody wins.

I think, too, another issue here is that we Americans, it's been my observation that nobody is quite as much like this as Americans, do have a propensity to look for quick answers, quick solutions. We hardly know how to accept anything in life that is not easily solved in a management-by-objective technique on a timeline. And when one has a handicapped child, the problem is never going to be totally solved as you know so well. So we have to fight this propensity of ourselves wanting to fix it all up and get it all at right angles and put it in a box and say, "Okay, we did that. That's the end of it." So this is the antithesis of how we think about everything else in our culture. When we build this collaboration, I think it is an even bigger issue to remember how long-term the collaboration has to be and how, if it isn't long-term, you'll never be able to help this child through his entire life.

We're here to explore the ways to build this partnership and I know that all the good guys and good women are here today to do this and it is a way to break down the walls and to build the bridges and I can't think of a more inspiring group of people than those here to do that. Thank you very much.

PANEL 1: OBSTACLES TO PARENT-PROFESSIONAL COLLABORATION

CINDY BOATMAN

Cindy Boatman is the mother of four children and two stepchildren. She was an undergraduate at the University of Maryland and Kansas State University. Ms. Boatman is presently working on the formation of an advocacy and support group for the parents of children who are seriously emotionally and mentally ill. She has also been involved in several research projects concerning the needs of the parents and families of the emotionally and mentally ill child.

I would first like to take the opportunity to thank Barbara Friesen and Portland State for asking me to come down and tell a little bit about what we have experienced as parents, which has not been a very nice experience. I am the step-parent of a seventeen year old schizophrenic. When Tommy came to live with us, he was about fourteen years old and we knew that things were not okay.

He was in the school system. We went to the school system and said, "We need some help." The school system said, "Well, what do you want us to do?" We said, "Well surely there is something somebody out there can do." They said, "Well, we suggest that you get him into counseling." We proceeded to do just that.

We contacted a family social service organization in Topeka. It's a super organization. You pay according to your income. It's on a sliding scale. They were more than willing to accept whatever our insurance would pay, plus whatever the insurance didn't pay then became our responsibility, but only on a sliding scale. That worked out fine. After several months of intense therapy, twice a week--family therapy and individual therapy--things had grown worse at home. Tommy was uncontrollable. The family as a unit was falling apart.

We called the psychiatrist and the social worker and said, "What do we do? Where do we go for help?" They had no idea where to go or what to do. Their only solution was to "Hang in there. Things will get better." Things weren't getting any better. Tommy was completely out of control. He heard voices. The voices told him to kill people. He was stealing. He couldn't function at school. He was failing all of his classes. We called the school again and asked, "What can we do as parents to get some help for Tommy?" Their response was, "We don't know. There is nothing we can tell you. There's no place to go. You're a parent, so you deal with it."

You bet you deal with it. You are alone. You are out there by yourself and have five other kids in your house. You are scared. Your family doesn't understand what is happening. You can't talk to the neighbors. They sure don't understand what is going on. You've got no place to go, nobody to ask and the professionals can't tell you what to do, except, "Things will get better."

Tommy was finally committed to the psychiatric unit of the local hospital because he was so out of control. For two weeks while Tommy sat in the psychiatric unit we thought that this was being billed through the service or the institute where we had initiated the services. The physician was on staff at the Family Service and Guidance Center. We didn't realize that once Tommy had been committed to the local hospital, that he became a private patient. So, instead of paying on a sliding scale, we were billed one hundred dollars per hour. The insurance had run out in the meantime. The hospital bill is ten

thousand dollars. We have two thousand dollars in expenses for a psychiatrist and still the situation isn't any better.

They said that Tommy's need was for long term treatment in a state mental institution. The state mental institution is full. You can get on a waiting list, which we did. Eight months later, after Tommy had committed a crime, and the situation was completely out of control, you bet we got committed to the state mental institution. And you know what their answers were? "We don't know what the problem is. We don't know where to tell you to go for help, but he can stay here on a temporary basis. Ninety days."

The situation isn't any better. There aren't any services out there. We are still looking. We still hope every single day that somebody out there, somebody somewhere, will help us as parents to understand what we are going to have to face and what every family of a child who is mentally ill is going to have to face. But up until this time I haven't seen anybody and I haven't had them call me and I haven't had them come to my door. Let me tell you, I have had lots of parents come up to me and say, "Oh, it's so nice to know that somebody else is going through the same thing we are. That there is hope, that there are other parents, that we aren't the ones who are the bad guys. That's what we have been told so many times. So many times the psychiatrists have sat on the other side of the table and said, "Hey, if you'd of done this or you'd of done that, things wouldn't have gotten out of hand."

But they didn't live at my house and they didn't walk in my shoes. They didn't live with that child twenty-four hours a day. I had to quit my job and stay at home. You couldn't leave him there with the other children because you didn't know what the end result was going to be. When you went to the professionals for help, they couldn't tell you where to go or what to do either, except, "Things are going to get better." It's been two years since all of this started. The situation isn't a whole lot better.

Tommy doesn't live in our home anymore. In order to get Tommy placed in a group home when he left the state hospital, we had to sue the Social Rehabilitation Services in the state of Kansas to get him under their care, custody and control. Otherwise they were going to put him on the streets. As parents, that was our responsibility to deal with that.

We were never allowed to know what the treatment was that had taken place at the Topeka State Hospital. We still don't know. We tried to talk to doctors. Nobody would talk to us. We were the lowly parents. The only thing we ever got were the bills. We knew how much money it cost, but we couldn't tell you what they were doing and to this day we don't know what they did.

Tommy lives in a group home now and he is under the care, custody and control of the Department of SRS. In order to do that we had to go to court, file a suit, pay for attorney's fees--not only for ourselves--but for Tommy to be represented. His rights had to be protected, but nobody gave a damn about the rights of us as parents. Nobody. Nobody one time said to me, "Hey, you have rights, too. You have the right to know what treatment we are going to give your child." We have the right to see those records, but we never did.

I guess my biggest hope and one of the biggest reasons I'm here today is that you professionals who are sitting out there, God, please, please give us parents a break. Listen to what we have to say. Help us if you can. We live with these kids. We know what it feels like. We need your help, but you need ours,

too. You can't possibly know what it's like to live in that home and not know from day to day what's going to happen and not know where to go for help. So listen to what parents have to say. Listen to what their needs are. Support us. You have to be able to listen and hear what they have to say. Don't think that we are all some horrible, terrible creatures that live out there, 'cause we're not.

We cry, we hurt and we need and we want our kids to be okay. But sometimes that's not going to happen. And we know that. But we need you to be supportive of us as parents and to help us. So I guess my biggest thing today is if one of you out there today who is a professional can hear that and say, "My God, maybe there really are parents out there who feel this way, and go back and at least listen, it won't be for nothing that I was here. Thanks.

RICHARD DONNER

Richard Donner is a social worker and a Licensed Clinical Specialist in the State of Kansas. He is currently a doctoral student in the Social Work program at the University of Kansas. Mr. Donner has extensive experience with children and adolescents both in direct service and administration over the last 15 years. He is currently the Coordinator of the Family Input Project of Child and Adolescent Mental Health Services in the State of Kansas. His research interests are in the area of family self-help, advocacy and support groups.

I think it goes without saying that when I started this experience, when I met with the first group of parents in Topeka one year ago, it became my biggest, most significant career change. What Cindy said and what the other parents said in that meeting probably had the most profound impact on me that I've ever had in my life. I'm a clinician and an administrator with fifteen years of experience in the field of mental health, specifically with children and adolescents and their families. I had to sit there and listen to the experiences that these parents were sharing and bite my tongue. It wasn't very pleasant to think about the fact that as a professional who had always thought that I was doing what was helpful, that many times what I had done or what I hadn't done may not have been helpful at all.

I think that Cindy's comment about listening is probably one of the strongest themes that comes through from all of the parent groups I've met with across the State of Kansas. In the last three months I have been in five other communities. Some of our very large communities in Kansas and some of our very small rural communities. Some of their issues, and definitely their stories and their experiences, are very unique, very individual; but there are some real strong themes which come through and across the board in terms of their experience with the systems.

As we all know, these children are not involved in just one system. They are not just in the schools or they are not just going to a mental health center. They are many times involved in four or five major systems. That alone can cause significant confusion and problems. It does for those of us who are in the business and are supposed to know it, much less for a parent who first tries to enter the system in one way or another.

The themes that parents seem to give me in the beginning stage of reviewing some of the information I am getting back seem to fall into three basic categories: (1) lack of services or lack of availability of services; (2) attitudes of professionals and behaviors of professionals; and (3) policies and regulations.

I want to share with you as best I can. It's awkward for me to be up here. I don't belong up here. Parents belong up here telling you the story. I wish I could have brought all fifty of them from Kansas and had them tell you. I don't mind being an advocate for them, but I sure don't need to speak for them. At any rate, let me try to summarize for you some of the things that some of the parents have shared with me in each of these three areas.

Lack of Services

Under the lack of services, of course, accessibility is a major issue. It's a major obstacle to even getting services. In some communities in our state, and I'm sure in other states, some parents have had to travel 60 to 150 miles one way for just a simple outpatient evaluation. Institutions are spread across the State of Kansas in such a way that sometimes parents must drive 200 or 300 miles if their child is in an institution. One of the issues parents bring up over and over again is that there's only inpatient, institutional, or outpatient services. Outpatient meaning one hour a week if you can afford that. Inpatient meaning 24 hour a day residential. Nothing in-between. In fact, when I meet with them and we talk about it, I ask them questions about in-home services and things like that. They don't even bring them up. They don't even think that such services are a possibility because we often don't have them and if we do, they are not where they are needed. In western Kansas, for example, to have an in-home service kind of component offered to these kinds of families is almost unheard of. We don't even have them in our major communities, much less in a rural area in which there may be one farmhouse every 25 or 30 miles. One of the issues that Cindy mentioned and that comes up frequently is that it takes so long to get help. Even the help in the services we have will take anywhere from three months to six months or even two years. Parents will go through many, many horrendous experiences. I can't even describe what it must be like for them not to be able to get the kind of help that they need or to be placed on waiting lists of eight months or more to even get in to have an evaluation to determine what's going on so that the services we have can be put into place.

Similarly, and I'm sure it's true in other states, there is no central place to refer parents to call. They call all of the possible, potential helpers and are told, "Well, we don't deal with that kind of problem," or "We don't deal with that kind of kid," or "Well, that's over there. Why don't you call them?" A mother in Wichita told me that she spent time every day, throughout an entire summer, calling every agency in that community. Wichita is a very large community. It wasn't until she finally connected with one particular person at the end of the summer, that she was able to get the initial help she needed for her child.

Another problem in terms of non-availability of service is the notion that we have to treat these kids away from home. All of us who are helpers in this profession have this idea that we need to remove kids from the home. We've done a lot of work. Portland State has worked hard on permanency planning. We've tried to place children in stable homes. I don't disagree with that, but we are finally developing theories and beginning to take a look at ways to treat these children and their families in the home. We are trying to preserve the family and not break it up. Many of the parents that I talk to tell me that if these efforts had occurred early on, they firmly believe that their child would have been able to stay in the home and that they would have been able to maintain that. The child would never have been institutionalized.

For those who do go into institutions or come out of group homes, one of the

major issues parents talk about is that there is no aftercare. There's no followup. The kid may do well in an institution or a residential home for a period of time, but come home to no services, no aftercare, no followup. The parents are right back in the situation they were in before.

When these children come home, or even before they leave, there is no respite care for these parents. They can't get away from the kid. I have a story about a mother who said that she literally had to lock her refrigerator because her child would overeat so much that there was no way you could leave that child alone. Who's going to go out and hire a babysitter for a seventeen year old? There is no qualified child care. There is no place for these parents to let their child go to for a brief period of time so that they can get away and do some of the things parents need to do or spend time with other members of the family.

No summer programs is another obstacle. During the school year if the children are at home and going through a PSA class, that works out fine. But what happens during the summer? No specialized programs.

One of the issues that was raised in all of the communities a number of times was one that Cindy raised and that is that there are no parent support groups. There is no place for parents to go to to talk to other parents. When we started out doing this needs assessment--which has now developed into what I hope to see as a model for the development of self-help support groups for parents of emotionally disturbed children--that came as an afterthought. A support group wasn't what we had planned. That wasn't something that we had originally thought was going to be the case. In the first meetings that I held with them, these parents found that they were not alone. For the very first time many of them met with other parents with similar kinds of problems and issues. Even in two very short meetings they were able to get support and feel different about themselves than they had before that. That's another one that I think we really have to take a serious look at.

Professional Attitudes and Behaviors

In the area of attitudes of professionals, it doesn't give me much pleasure to share most of these. They aren't positive. That isn't to say that there aren't positive, caring professionals out there. A lot of parents, as they tell their stories and their experiences, share with me, "There was one. If it hadn't been for him or her I don't know how I would have made it." So, I temper this with saying, this isn't all of us. Some of us have got it together out there. I'm not sure who. I may start going and finding out and writing a book about it. Maybe we can do some changing, but most of these parents have experienced an intense amount of blame from professionals.

Professionals have referred to parents as bad guys, outsiders, dumb, interferers, sick, needing to be evaluated themselves and so dysfunctional that they could no more share information that was valuable than could a person who was institutionalized as a chronic schizophrenic in a state hospital. Adoptive parents don't have it any different in terms of dealing with it. They have to deal with the very same issues. Even foster parents who have come to our meetings feel exactly the same way. There are no answers and so they are blamed. They continue to feel crazy and end up on the other end of going to get help and feeling that they are the ones who need more help, that they really are the ones who need to be institutionalized. Maybe there is something wrong with them, that it is not just that their child has emotional problems and they have

things to deal with.

Another issue in terms of behavior of professionals that I think is a serious obstacle is not involving parents in the treatment process or the decision process. I don't mean making the decisions and recommendations and then coming and telling parents, but involving them in that process. Most of the parents that I talked to are not involved in that. In fact, they are told not to even participate in treatment. It interferes with the treatment their son or daughter is currently receiving. One parent was told that they make things worse when they saw their child in the state hospital. They were told they should not come up and see their child. They didn't come back for three or four months.

One of the things that happens with professionals, I think, is that we try to assess too much. I think it becomes a real obstacle because a parent will sit there and express out of frustration the fact that things are so terrible they would literally like to throw the kid up against the wall. They just can't take it anymore and feel like they would just like to slap them or something. A professional who hears that--and doesn't hear that it is out of the parent's frustration--hears that the parent is going to abuse the child. SRS is now going to investigate them. That has happened. It has happened to the point where parents refuse to say anything in staffings because they are so afraid that they will be misinterpreted and misunderstood. It will only make their problems worse and their problems are already bad enough. They don't need more stuff on top of them and more lawsuits.

Another issue is that parents find professionals won't listen to them. I can't emphasize that enough. It is like they are not listened to at all. One mother described a situation to me in which she sat in the social worker's office and shared all of this information about the problems their child was having. The social worker sat there and did a very good job of taking good notes. She then turned around and shared all of that information right back to the parent as if the parent had never said it. As if the parent had never even mentioned it. As if it was new to them. The mother looked at her and said something to the effect of, "We know that. That's why we are here." The social worker was dumbfounded. Somehow the family had come to this understanding and insight without information from professionals. There is something wrong with that.

One of the things that is a major barrier for parents is that their child has to go through a major crisis to get help. Cindy's situation, she didn't go into it in much detail, but her son had to get involved with the court before they were finally able to get help. The kid has to make a serious suicide gesture before the system will open up enough so that the child can be placed on an evaluation unit in an acute psychiatric unit. Those are just a couple of examples and you could all tell many more.

Back to another one of those attitudes and behaviors of professionals that aren't very helpful. Many times parents have other responsibilities. This may come as a shock to some of you, but they don't have just one child and one life that they can focus all of their energies on. They usually have homes and cars. They usually have bills to pay and many times have other children. Those other children have needs too. And so do those parents; yet, when these special children go into certain institutions or agencies to get help, the agency views the parents' need to do other things as resistance. They tell them they can't make it to appointments because they have got to get to the church social. They would like to see some friends and they are told that they don't care about

their child. They come fifteen minutes late to a meeting because they had to take two other kids to doctor's appointments and it is interpreted as if they don't care about their special child. And it is even interpreted that way to the child. Again, just a couple of examples of that kind of thing.

Another one of the attitudes that I think professionals hold that is an obstacle parents have shared with me is that systems don't work together and professionals don't talk to each other. As a result, they have to go through the same stuff over and over again. That is not an exaggeration. I know of examples of parents who have gone through probably four evaluations before they finally could get help for their child. Do you know that none of those evaluations looked the same? None of those evaluations were shared with the others, nor did all of the people doing them ever get together to talk about what was going to happen. The parent just kind of ended up going with the last evaluation and doing what needed to be done because by then they are so frustrated and dumbfounded and don't know which way to turn. If someone points them here, they'll come here. If someone points them there, they'll go there.

Another attitude of professionals which definitely becomes as obstacle--or maybe it is a lack of understanding on our part--is a lack of early recognition of the kinds of problems these children and their families face. This causes a great deal of difficulty for the families. They may spend many years bucking their heads up against many different walls.

Policies and Regulations

Let me just quickly summarize what the policies and regulations kind of obstacles are. Cindy has already mentioned that insurance runs out. If you don't have insurance I hope you have some very wealthy family members, because it is going to cost you a lot of money--anywhere from 10 to 60 to $100,000 per month for these kinds of children to be treated in residential, group or private type facilities. In our state we have a really deplorable situation. It isn't unique to our state according to Jane Knitzer and her book, Unclaimed Children.

Many times the only way parents can get help for their children is to turn them over to the welfare department. In our state it is called SRS. I have had parents who told me that they literally had to prostitute themselves in front of the court and say that they were neglectful parents so that they could get the kind of help that their child needed. This was for no other reason than money. The only way they could get payment for the kinds of help their kid needed was to turn them over to that kind of agency on a temporary custody basis. I don't know how in the world it must feel for a parent, but it has got to be one of the most horrendous feelings inside to feel like you are turning your child over to get help when you are already feeling really bad anyway and guilty and shamed and everything else. To add that one more component on has just got to be horrendous. It's no wonder those parents sometimes stay away and don't want to be involved.

Other issues are around adoption. Parents of adopted children many times don't get information. They aren't told what is going on. Adopted parents have told me stories about not having accurate information in the child's records and, of course, they aren't allowed to even see them. Ridiculous kinds of stories around what happens with that in schools, PSA classrooms or IEP processes. Not being able to access the records is a horrendous problem sometimes.

94-142 is wonderful and parent involvement is great, but when the professionals

put it all together and tell you what is going to happen, as a parent you don't feel like you have anything to say about it. I have heard story after story from parents about those kinds of issues and games.

The school system suspends their child for the problem behavior that resulted in their child being placed in the PSA classroom to begin with. Parents say, "What the heck are we supposed to do? The kid is there and you are supposed to be helping us deal with this child. And what you do is send him home to me because he flipped somebody off when that is part of the thing he is in here for." It is unbelievable stuff.

One of the issues that I think relates to policies and regulations is access to records. Access to records is something many parents don't think they have. They don't think that they have the right to look at their child's records. They do. Let anyone in this room who tries to tell you otherwise find the state statute or federal regulation that says that--because you do have the right. But--listen to this one--it's even worse when you see them. Parents tell me that there are so many inaccuracies in those records just on factual information --not opinions and impressions, which they understand the professionals are going to put in there--but just factual information.

I have to tell you a story about an adoptive mother in Wichita. She adopted two twins when they were seven years old. That mother has now been investigated by our SRS Department because of an inaccuracy in a record which was written about one of the twins. One of the twins was at the state hospital. The state hospital record said that this mother denied that these were her children. She has legal documents that prove that these children were adopted but somebody, somewhere messed things up. So she now is being investigated by SRS and was referred for treatment because she denies that these are her children. It is that kind of stuff that is ridiculous. I won't go on any further about that kind of thing.

Another issue that parents mention a lot is the fact that confidentiality between systems is really a systems cop-out. They could share. They talk. They know what is going on and yet they tell parents that they have to sign sixteen releases and, "We can't do this," and "We can't share that." Those policies become major obstacles to parents and professionals working together.

Lastly, there is the issue of the fact that the rights of parents are not written anywhere. I remember asking around in our state, asking legal people, "Is there something written up? We have handbooks written about everything else. Don't we have a handbook on what rights parents have?" "No, there is no such thing." I'm going to talk to Judy later today and we are going to see if we can get something out of NIMH to get that done. I think it is about time.

Let me just close real quickly with the fact that I think the words that Cindy and other parents have used have changed my whole focus and my career professionally. I can't thank them enough and let them know how much I appreciate what they have been able to do for me. I can only challenge everyone here to take the opportunity and make the opportunity to sit down and listen to the only real, true experts--the parents. Thank you.

JOHN MORGAN

John Morgan, Ed.D., Administrator of Community Rehabilitation in the Department of Health and Welfare in Idaho since 1981, began employment with the Department over 15 years ago. The Division of Community Rehabilitation employs about 1,400 staff and has an annual budget of 41 million dollars to carry out its responsibilities for mental health, developmental disabilities, and institutional youth services in Idaho. He has worked in youth services, mental health, and developmental disabilities programs as a psychologist. He is a former assistant professor and director of the graduate counseling program at Lincoln University in Missouri. While at Lincoln University he held an adjunct appointment as a counseling psychologist in the Counseling and Testing Center. He has also served as a consultant to Head Start Agencies, the Missouri State Department of Education, and a variety of social and health service agencies.

When I was asked by Barbara Friesen of Portland State to come to this conference and talk about obstacles to parent and professional collaboration, I spent a good deal of time thinking about whether I should talk about Gramm-Rudman, talk about state general fund shortfalls and holdbacks, the unresponsiveness of the Idaho Legislature or the problems of geography as far as population is concerned. Finally, I concluded that while I could come here and talk about the many different kinds of obstacles and barriers that do exist between parents and professionals, maybe I should share something in terms of my own personal experience and observations as a mental health professional.

For me, the single greatest barrier to effective collaboration between parents and professionals is lack of access to meaningful treatment programs for their emotionally disturbed and handicapped children. This comes about, I think, in part, due to the fragmentation between professionals, and between professional caregiving agencies with regard to the direction, services and programs for children's mental health services.

I think that if we took the time to ask the organizers of this conference, they probably could relate to us some of the difficulties they have had in trying to bring together representatives from mental health programs, juvenile justice programs, child welfare programs and so on. I think that this lack of agreement upon the direction of children's services between professionals and state agencies results in frustration, confusion and anger--not only between professionals and agencies--but frustration and anger between parents and agencies.

I think that all of us in this room today know, perhaps to a greater and lesser extent, what some of the problems are. I think we are less apt to know what some of the solutions are, which is why, in my judgment, a meeting such as this is both relevant and important. I think that, if nothing else, we need to be mindful of the pain and anxiety that are experienced by parents of emotionally disturbed children and aware of their frustration as they attempt to get the professional services they know their children so desperately need.

If nothing else, I would hope that we can all leave this conference two days from now with a sense of renewed encouragement that the sense of discouragement experienced by us as parents and professionals will be lessened, because discouragement is not only a symptom. If left unchecked long enough, it also becomes a condition. Let me close by saying, as I once heard it expressed, "We are all sick and tired of being sick and tired. Thank you.

GLENDA FINE

Glenda Fine is director of the Parents Involved Network (PIN) project which organizes self-help/advocacy groups for parents of emotionally disturbed children and adolescents in Philadelphia under the auspices of the Mental Health Association of Southeastern Pennsylvania. She is a member of the Pennsylvania statewide CASSP Advisory Committee and the Pennsylvania Bureau of Special Education Audit Team. Ms. Fine is on the staff of Project PIPE--Parents in Partnership with Educators--a federally funded project under the Pennsylvania Department of Special Education, and formerly on the staff of Project PTP--Parents Training Parents--also a federally funded project under this department. Ms. Fine was also formerly on the staff of Parents Union as a special education advocate.

Actually, Richard said everything I wanted to say and I could really just sit down, but I will bring some different perspectives to the subject. First, as a parent, and secondly as an organizer of self-help groups. Everything I will say today will be from the parent perspective.

One of the parents in our Philadelphia group wrote a very short page on how she felt about self-help groups and I'd like to read that to you today.

> So many of us struggle to be good parents in an anxious fog of self-doubt. Too often eager experts raise more parental self-doubt and diminish self-esteem.

Before I go on, I don't think you'll find me to be very polite today. We were talking about getting out the negatives and being polite, but I'm not in a very polite mood. I am going to say it as it is. So let me finish reading this nice article.

> Parents in self-help groups run by parents decide for themselves what they need to do. They organize or join a group with other parents, depend on one another for emotional support and practical guidance and in most cases unite with each other to challenge institutional and political decisions that harm or threaten their children.
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> Within a self-help group, such as our group, which is Parents Involved Self-Help Network, parents build new communities for each other, develop self-confidence and make positive alterations in their self-images. They learn that the power of the professionals is not magical and become experts, not only in the areas around which their support group was formed, but also able to provide services to other parents.
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> Self-helping parents are in a unique position to empathize with the parents who call on them and are accessible in a way that professionals seldom are. Their concerns go beyond their own children and beyond the children of other parents who call on them for help. These parents almost always become interested in changing the institutions that provide services for

> their children and reforming the laws that govern these services.
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> An important point is the passion that parents bring to advocacy for large scale change springs from their own acute, painful experiences. Resourceful parents can make our policies, institutions, agencies and governments vibrant with respect for the power--and that's a big word--the power of parents. By depending on ourselves, making demands on the system, fighting for our children, parents and professionals can work together to try to get services that meet the needs of our children and to make professionals responsive to parents as well.

That's what one of our parents wrote.

Now I will talk on a personal basis. First, as the parent of an emotionally disturbed adolescent. I will jointly talk about attitudes that I have encountered and what I have perceived to be barriers to parent-professional collaboration. I will throw in comments from other parents in our group. What I think I really want to focus upon, because Richard and Cindy did tell it all, is what happens when professionals encounter knowledgeable parents?

Let me start from one meeting I went to when I first had to go to the children and youth system in Philadelphia to turn the custody of my child over to the state. I had to declare him incorrigible. I was not thrilled with that, but that was the only way I could get services. There were no alternatives. I will get back to that.

This social worker--well, whatever he was--said, "Do you know how to write your name? Because I'd like you to write your name and address for me." I was still being very nice because, in my experience as an advocate for special education, I learned that you get more with honey than with salt, so I just said to him, "Yes, I can write my name." "Good, could you write it legibly or do you have to put an X there?" Well, by this time I was really wondering what I should do. Should I give it to him straight, or should I just see how he is going to treat me. Anyway, I wrote my name and address. He said, "Now, what did you do to your kid so that you have to declare him incorrigible? Do you have to give him to us to pay for because you don't know what to do?" I won't go into what I said to him or how I said it, but when I left, I assure you he knew I'd been there. In fact, he called the security guard.

Another attitude that knowledgeable parents encounter is great resistance from professionals. I have found, and other parents have found, that professionals in the mental health field like to become parents to the parents. But when they have a knowledgeable parent, whether that parent has a Ph.D. or has graduated from the second grade, doesn't matter. Your knowledge is what matters--the way you have learned to negotiate the system. Your training is the reading you have done and training you've received--possibly through the school district if your child is in special education. Anyway, I think that professionals are very resistant to knowledgeable parents. I think it is a matter of power. Professionals like to have the power. I will say to every one of you here, while they have the power, they are in control. Since the parents did a lousy job while they were in control, how could they be in control with the professionals? I don't know that that came out right, but I think you know what I mean.

Professionals look at knowledgeable parents as intrusive, as trying to run the show, as trying to--God forbid--be involved in the treatment plan. Really, knowing too much is what makes the professionals feel uncomfortable--very uncomfortable. One parent said, "When I went in and they asked me what I was besides being just a mother, and I told them I had a Ph.D. in chemistry, the professional almost fell off of her chair. She could not speak." She did not know what to do with this parent. She had to call in her supervisor to take over that intake session, because parents of emotionally handicapped children are viewed as if they don't have even one marble in their heads. Okay, so I think you have my feelings on professional attitudes. I don't have to go into it any farther.

The other thing is, how can there be collaboration when parents with no other alternatives must give up custody of their child? Giving up custody in order to obtain services immediately takes away the parents' feeling of being the parents because someone else is taking over the parental role. Collaboration falls apart once the caseworker says, "We have custody of your child. We can do what we want now." Fortunately, in my own situation the caseworker was very nice. He said, "Your child does not need a state hospital, but he does need a restrictive setting, so he will go to such and such a place." I asked what mental health component there was there. He said, "Oh, they have social workers and a psychiatrist who lives on the grounds."

One of the issues which has nothing to do with what I'm talking about right now is that there is very little for children who do not require state hospitals, but are still required to have a restrictive setting. That's a whole other issue.

Many caseworkers will tell you that the only reason you are turning over custody is because otherwise they could not get funding for your child. I think that is something that has to be looked into by every state because it's a very cruel way for parents to have to use to get services. Parents feels very debilitated by the whole situation. They have been living with it for years. Their child is ill and they have to go into a court hearing and have a judge say, "Obviously you cannot control your child, therefore we must take custody of this child. You are a neglectful parent and you are making your child a dependent of the state." If any would like to talk about this later, I'd be glad to discuss more about how a lot of parents feel.

When children are in residential placement centers, they see a social worker once a week. In my own particular case, my son was in a residential placement center for a year and a half. Now we have to remember in these residential treatment centers, children are told when to get up, when to eat, when to go to school, when it is rest time. It's very structured. Then they come home. Oh, well, let me go back. They said it's time for Josh to come home.

As my own worst advocate--it's amazing. I go and advocate for other parents, but when it came to my own son, I made the biggest mistake that parents make. I took no one with me. I thought to myself, how can I tell them that he's not ready to come home? They must know. I fell into that trap all by myself. They didn't know. They didn't do any planning. There were no transition services. There has been no follow-up. I have received not one telephone call asking, "How is Josh doing?" Not one.

Josh came home at Thanksgiving. I felt that maybe things would be different,

because I, too, am looking for that eternal miracle that never occurs. Things have been falling apart since Thanksgiving. My son was not going to school. Fortunately, I got him into a private school placement, but he doesn't want to go there.

I have driven to the river once or twice and looked in and thought, "Would it be easier just to go in there?" I know that I can't do that, but I know that when I go home my other personality takes over. I say, "I can't do anything about this situation. There is no one out there to help me and I don't know what I'm going to do." I become very passive and depressed, but people don't know that because I am really a very good actress.

Now that he's sixteen, I don't know what is going to happen next. He doesn't want to go to school. The truant officer called and said, "What are you doing? Are you in therapy?" I said, "Yes, we're in therapy. We're doing this. We're doing that. We've done everything, but nothing helps."

Again, I have to reiterate, this child does not need a state hospital, but he is socially and emotionally immature. I, too, would have to lock the refrigerator if I had the guts to do that because my food bill now with my younger son and with Josh is about $125 or $150 a week. That is just for the three of us. There is nothing I can do with him.

I am working with a caseworker in the children and youth system. Perhaps he will have to be placed again. What will happen when he comes out again? The same thing. So, what we need to do, what parents need to do in working with professionals, is planning for kids who do not need restrictive settings, but cannot live in society as they are, which describes my son. I don't think he will ever be able to do anything. Maybe he'll be able to wash dishes. I'm not sure. This is something that special education, with all their knowledge, has not really worked on. That's another issue.

I have a lot of issues and I can't go into all of them today, but what happens to kids as they come out of SED and LD classrooms? Are they really prepared? My feeling is that they are not prepared when they come out. They learn how to read and write to the best of their ability.

I see that they are looking at the clock. I might be talking too long. I really need a whole day and I haven't found a forum for a whole day yet.

So, I want to end this very quickly by saying, regard the parents as the people who have the most input into their children, into the knowledge about what their children need. After all, these are the people who live with the children 24 hours a day. Don't look down on parents because, except for the grace of God, you too could be the parent of an emotionally disturbed child. That's something to always remember. Never judge someone, I think the saying is, until you have walked ten miles in their shoes.

Let me tell you, as professionals, you are not in our homes. You were not in my house at 10:30 at night when my son threw my dining room chairs out of the window. The neighbors called the police. They said, "That crazy lady can't control her crazy son." I stood there and cried because these neighbors don't understand. How could they understand?

One other fact I want to bring up is the fact that as a single parent on a block with all married couples, my kids were always blamed for everything. I was

always the parent of that crazy kid, as I said before. The records we keep of parents who call and want help with our groups show that the majority are single parents with male children. That's just an interesting aside.

Anybody who wants to talk with me later on, I would be very glad to talk with you.

ANTHONY ZIPPLE

Anthony Zipple is a full-time Research Associate at Boston University's Center for Psychiatric Rehabilitation and a doctoral candidate in the Rehabilitation Counseling Department at Boston University. He has a decade of experience with community mental health programs. Special areas of interest include community residential rehabilitation, the homeless mentally ill, and the needs of families with mentally ill members. Mr. Zipple is currently revising an 18-hour curriculum designed to teach mental health practitioners to work more effectively with families of the mentally ill.

I'm really pleased to be here today. I do a lot of presentations around the country every year on family issues and a couple of other topics that I'm involved in--like the issue of homelessness at the Research and Training Center--but the ones I always enjoy best are ones that happen in groups where there are both family members and practitioners together trying to learn from each other, or consumers and practitioners together trying to learn from each other about how to address some of the thornier problems that are involved. I was very pleased to be invited to this and be with a group, again, of family members and practitioners who are struggling with very similar kinds of issues and trying to be helpful to each other.

As Tom said, at the R and T Center in Boston we have been involved for about seven years now in doing service work related to the needs of families that have mentally ill members and, in the last few years, have begun developing training packages for professionals. A lot of what I'm going to say has to do with what we've learned from the survey work we've done, which has been very closely linked with the Alliance for the Mentally Ill. I'll discuss what we've learned from the training we've done.

The first obstacle that I think is critical in terms of interfering with effective parent and practitioner collaboration has to do with the training that we've given to practitioners. Virginia Satir, who is a very famous family therapist, talks about families by saying that everybody always does the best that they can. I think that that is generally true about professionals, too. Most professionals that I have come into contact with genuinely do the best that they can. The trouble is that most of them haven't gotten the kind of training that they need to do the jobs that they are supposed to be doing.

The bulk of training for people who work with families and graduate schools in this country focus on blaming families either overtly or covertly for the kinds of problems that their ill children develop. They emphasize the role of the family therapist or the professional as being the expert and it is a very expert oriented kind of a system. Both of those things militate against there being any kind of real collaboration. That kind of a stance has continuing currency in most graduate training programs in the United States.

I had the opportunity to be part of a training group in Boston and sat through a session with a family therapist who showed a videotape of a therapist sitting

with the mother of a schizophrenic son who also had a non-schizophrenic twin. You watched the videotape and at the end of the videotape the therapist stood up and said, "Now, if you watch carefully, you can see that when the schizophrenic son said something the mother stiffened and pulled back a little bit. That explains why the schizophrenic son is schizophrenic and why the other one isn't because the mother leaned forward to that son."

Any of you who have ever lived with seriously mentally ill people know that there is some tension involved, especially when you are trying to sit with a therapist who isn't necessarily friendly to your cause. While I have never had the misfortune to be in that situation of living with an ill family member, I have run and lived in residential programs for a number of years and, let me tell you, the issues are similar. So, as a group of professionals, we just haven't gotten the kind of training that we need to do what families are asking us to do. We haven't gotten support from the people who have trained us and the people who have supervised us to do what we need to do.

As another anecdote, somebody that I work with in Boston--a family member who has done a lot of training with us--tells a story about his young son, 22 or so, who is living in a half-way house in Massachusetts. The family was told by professionals that their son was gong to move into a more independent setting and they didn't want the family to interfere with that. What they wanted the family to do was have no contact with their son for two months preceding the move and for two months following the move. No contact at all. No phone calls, no letters, no visits, nothing.

This advice was congruent with a lot of things that they learned in their graduate training programs about the role of the family and the development of the disorder and the role of the family in developing pathological dependence. Again, I'm not saying the professionals are bad people in doing that. They are doing the best they can, but the training that they have gotten is, by and large, abysmal.

Now, part of that is because there isn't much of a professional literature around this topic. Even with people with chronic psychiatric disabilities, even with that literature which is somewhat more developed in many ways than around childhood psychiatric disabilities, there is almost nothing written before 1978. The vast majority of what has been written has been published since 1983, so we are talking about an extremely new field. There just isn't a lot of professional literature out there for people to use.

I was at a meeting of the National Council of Social Work Education in Washington this past summer with a group of hot-shot educators from graduate programs of social work around the country and came to the conclusion that, even though there is more literature around now than there was five years ago, it's still not being used, by and large, in schools of social work in this country. Again, schools of social work are run by people with very different kinds of training.

There is a real need for current professionals to begin to give up some of what they learned in graduate school about families and about the relationship between families and chronic mental illness. That's a hard thing for a lot of us to do, because there is a lot of ego investment involved on the part of professionals. They paid a lot of money and went to school for a lot of years and worked very hard to get where they are now. Now they are finding out that a great deal of what they learned is either irrelevant or destructive to the

families they are supposed to be helping and they get defensive about that.

Basically, professionals have just gotten very bad training and there aren't a lot of graduate programs in social work or other disciplines that are doing a particularly good job, even today, of teaching professionals coming out of graduate schools how to do better. As a result, we end up with professionals who, as everyone on the panel has talked about, have poor attitudes about the families and have limited information about what families want and need from professionals. They have limited skills about how to provide that. I think that that in a sense is the first and foremost obstacle that we face in trying to turn the situation around of helping practitioners to work more collaboratively with families and vice versa. Professionals need better training.

The second obstacle that I think stands in the way has a lot to do with families. Even though families have gotten a lot pushier and a lot smarter about dealing with professionals and about dealing with the mental health system, they need to get much pushier and smarter still. There needs to be an even broader range of families.

Right now, you have a lot of families who are very involved in advocacy. We need to double that number in the next few years, triple that number in the next ten years and so on. As a group, families overall need to get a lot more assertive about what they want from professionals and a lot slicker about how to get it.

We talk with families about the need to subscribe to professional literature, for example, and to read the kinds of things that professionals read so that when they go in and advocate with professionals about what is best for their ill family member, they've got some kind of base that the professional can respect. That really cuts it. I like to think of myself as having pretty good attitudes about it, but the first time a family member said to me, "That's not what it said in the last issue of The American Journal of Psychiatry," it put me back a little bit. We tell families that they need to get smart by reading that kind of material and by being able to use that when they need to interact with professionals and advocate for their ill family members.

Part of that has to do with some of the work we have been doing on stages of adjustment to having a chronically ill family member. A lot of people have tried using things like Kubler-Ross' model of adjustment to death which ends up with some kind of adjustment and acceptance of death. We think that families need to do better than that and need to go beyond that.

The kind of adjustment that we think families need to get to is where they get into advocacy. Advocacy really needs to be the final stage of adjustment to having an ill family member. While a lot of families have gotten to the point of adjustment or acceptance, a lot of them still need to take it a step further and get into some hardball advocacy with the power brokers and the decision makers and with the individual therapists who work with their ill family members.

Something else that has been alluded to that I want to say just a little more about has to do with the fact that we are dealing with an extremely frustrating and badly understood set of disorders. I think it is a third obstacle. That drives all of us crazy, too. There is a tendency on the part of both professionals and families to blame each other for the fact that we haven't been

able to fix the problems of the ill family members. That happens especially on the part of the professionals blaming families, but I think there is also some of the reverse of that, too. In fact, in many cases, what the professionals are doing and what the families are doing doesn't have anything to do with the course of the disorder.

We can make people more comfortable and happier and so on. There are a number of good things that we can do, but in the long run, we're not going to be able to fix a lot of the illnesses that these family members have. The ill family members suffer from disorders that we don't know how to fix. It's frustrating for all of us involved and we need to be able to get to the point where we begin to see that both families and professionals are not really parts of the problem, but parts of the solution. We can work together towards dealing with a disorder that is pretty intractable and is frustrating for all of us.

A fourth area has to do with families and professionals often having somewhat different agendas and priorities than the other, and rightfully so. I don't think that families and professionals, even though they can work together in a collaborative way, need to agree with each other all the time about everything. I think that would be a little much to expect and that sometimes professionals want to be overly protective of the ill person and families are saying, "You need to push that person more." Sometimes the reverse is true. Sometimes families want to be overly protective of their ill family members and professionals are saying, "You need to push a little more and take a few more risks." Those aren't because either one is necessarily right or wrong, but just that they have differences in perspective. I think it is unrealistic to expect that those kinds of differences are ever going to be completely solved.

We need to be able to acknowledge that there are going to be differences and to work within those differences. I think that is one of the obstacles that we haven't gotten to the point where we are willing to acknowledge that there are going to be differences of opinion between parents and practitioners because they have different perspectives, different windows of experience. We need to acknowledge that and to move beyond that and do some things in spite of that.

Related to that, I think that there are some difficulties that practitioners face in terms of loyalties. Who is their primary client? In some ways, when you are working with kids it is a little bit easier because the family has every right to be involved. When that child becomes an adult at age eighteen some of the thornier issues around confidentiality and family involvement crop up. I can't get into a detailed discussion about all the ways that those crop up and ways to solve them in the ten minutes I've got, but they are real problems for professionals who are put in situations by mental health systems, their supervisors and the legal system. They need to make some decisions about where their primary loyalties rest--whether it is with the family or with the ill family member. Sometimes it is really hard to reconcile those as a practitioner.

As a field we need to work out some ways to begin to do that--to begin to develop ways that the families can either get what they need someplace else in a way that doesn't interfere with the kind of work we are trying to do with the ill family member so that we can bridge the gap more effectively. There are some ways to do that. If we had some more time we could talk about them. It is a thorny issue working with young adults 18, 19, 20 with chronic psychiatric disabilities and their families.

The last thing I want to mention is that I think--in terms of obstacles--that there is really a lack of systemic support for practitioners who want to work collaboratively with families and a lack of systemic support for involving families in that kind of process.

I have yet to work in a mental health clinic where the majority of treatment planning meetings happen in the evenings when it would be easier for family members to attend. They are set up for the convenience of practitioners. That's the way the mental health centers operate. If the individual practitioner wants to do it differently and, perhaps, have the meetings in the evening when it would be easier for the families to attend and says, "I want to do this," there are fourteen reasons why they can't do it. "The building isn't open. They don't have security. We've got people coming from all of these other settings and what would it mean in terms of our relationships with other agencies if we told them, 'We want you to come at 7:00 pm. in the evening'?"

There is not a lot of systemic support for involving families more. In some agencies there are families on boards of directors of mental health centers and mental health agencies, but not nearly enough. We haven't yet given families the kind of power and control, the kind of clout, that it would take for them to really make some kind of impact on the systemic support, even though there is a lot of talk about empowering families.

It's a funny thing about power. There is not an unlimited quantity of it around. No other group gets empowered unless some other group is willing to give up some of their's. As a mental health system, as a group of agencies, I don't think we have been very good about giving up some of our power and control over the system and turning it over to families.

You know, it is real scary for mental health practitioners to say to families, "You're going to be on the boards of our agencies," "You are going to be involved in evaluating the quality of individual practitioners involved in that agency." That's the kind of systemic opening we need to make for families if we are really going to begin to bridge the gap that currently exists between what families say they want and need and what they are able to get out of a system that is often unresponsive for both good and not so good reasons.

Since we only have about ten minutes left, I'm going to stop so that there is some time for questions. If you're interested in the kind of work we are engaged in what we do to train practitioners, I'll be doing a workshop later in the afternoon.

LUNCHEON ADDRESS

LAURIE FLYNN

Laurie Flynn is the Executive Director of the National Alliance for the Mentally Ill, a network of approximately 600 family advocacy groups throughout the country. Ms. Flynn has also been Executive Director of the North American Council on Adoptable Children and the Pennsylvania Coalition for Children. Like all NAMI members, she has personal experience with mental health services as one of her 12 children has experienced a serious psychiatric illness.

I want to talk to you about something special that families bring to the mental health system . . . LOVE. Love is an often misunderstood word. It is usually used to signify romance. When we think of love we think of Valentines and we think of songs on the radio and maybe we think of romantic weekends. I think it's very important for us to recognize that the word "love" is a verb. It is a verb, it is an action word. It is a word that denotes not just feeling something for somebody, but more to the point for us as families, doing something for somebody. Love reaches out, love puts up with, believes in, prays for and hopes for and is certainly working hard for the future for our children. We only want for our children what every family does, what your family does, what all American families do; an opportunity to be successful and to share'a life that has meaning.

You know, families have been kind of rediscovered recently. After about two decades of tremendous change in our society, and enormous stress on our so-called helping systems, we have come in some ways to the limits of what we can currently do with external help. And so we're taking another look at families, looking at them with renewed respect and interest, seeing families for what they are: the primary care system for almost everybody, the only ongoing case management for almost everybody, and the only accountability for all of us.

It's been my belief throughout all of my work in the last decade on behalf of children and families that we begin to have health in any system when we begin to move over and listen to the family voice as we shape family policy. Sometimes that's a little difficult so maybe I'll try to illustrate why this is so important with a little anecdote. It's the story of three stonecutters. Three stonecutters were working at a big construction site and somebody walked by and asked the first stonecutter, "What are you doing?" The stonecutter looked up and replied "Well, what does it look like? I'm making blocks to earn a living." So the wanderer went to the next stonecutter and said, "What are you doing?" The next stonecutter looked up and pulled his shoulders back a little bit and said, "I'm becoming the best stonecutter in the nation." And the wanderer went on to the third stonecutter and said, "What are you doing?" And the third stonecutter looked up with a great deal of hope in his eyes and said, "Why, can't you tell? I'm building a cathedral."

Now it's important to know that when families approach a system that's going to serve their family member, they feel about it the way that third stonecutter felt about his work. Parents want to make something solid. Parents know that it takes a step-by-step, careful process and that it's not going to be easy. But then parents have a long-term goal in mind. We're building a future for someone we love; and remember now, love is very powerful. We're building something that we believe should last far beyond our lifetime because we don't know when our child's needs will end. We know, many of us, that nothing miraculous is going to happen when our disturbed adolescent becomes 18 or 21. Some of them

are still going to need services, and sadly some of them may not find the services they need. So we're in it for the long haul. We're in it to build the cathedral that is worthy of our child and our child's special potential.

I want to talk about children. I talk out of experience. I have twelve of them. I have twelve of them because I am a fool. Right up front I'll tell you: they were right over at the mental health clinic, I am crazy. I have twelve children because I just think it's exciting to see what you can do one-to-one, or one-to-twelve, or one to however many. But I want to talk to you today about the two reasons that I'm here. And I think we all as parents never move away from remembering that the mental health system is not to us a bunch of boxes and charts, it's not statistics, it's not budgets and programs, it's not even conferences. It has a name. It's our child. If the mental health system works for our child, it works for everyone, it's wonderful and terrific and we stand up and applaud it. If it doesn't work for our child it can't be saved, it's in need of revolution and reform and may never do the right thing again. We all go from our own experience. I've had several experiences and I want to talk to you about my two children who are currently involved with the mental health system. Although I've had, as you might imagine, lots of other opportunities to interact with the system with other children.

My first-born child is a beautiful 18 year old named Shannon. Shannon was reading at four, she was precocious beyond her years, multi-talented, gifted even. A straight-A student from the minute she walked into school. A musician, an artist, she's had shows, she's performed publicly. She went to the Governor's School for the Gifted. She's had a nationally recognized essay published. Here is the perfect child. Here's the child who's selected from all the rest of the county to a special physics prize. This is a little girl who volunteers to teach English to Hispanic youngsters. This is a child doing so well you almost don't notice. But unfortunately about 18 months ago this is also a child who gradually became more and more withdrawn. We felt it was just busyness, all her senior year activities. Eventually she became disturbed enough that we thought she ought to see a psychologist for some counseling. It's hard to pull away from a big family and make decisions and we were ready to get that kind of help. But she rapidly disintegrated into panic attacks, into real psychosis, stopped eating, stopped talking, and really went literally right over the edge. I've been through a lot in my time but I have never been through anything quite as terrifying as watching my child become literally a stranger. Well, we had to, after a number of efforts and everything else failed, hospitalize Shannon. And that was probably the most galvanizing experience of my life. We took her to a local private facility, using insurance money. We got to be familiar with the insurance crisis only after we'd spent a lot of our insurance coverage. We found that in the hospital setting we were not people who needed to be consulted. We were not people who needed to be informed. We were pesky, however, and insisted and showed up every day and we were then "meddling and troublesome parents" who wouldn't "let go" of our child.

We noticed some things in the setting that were troubling to us. In the same hospital unit were about 25 adolescents, all of them received exactly the same kind of care. We asked for a treatment plan. They gave us something that had been xeroxed. That was everybody's treatment plan. We asked how in the world they thought the same course of therapy could be helpful to a severely depressed child, to someone who was involved in detox from drugs and alcohol, to a child who was anorexic, to a child who was hostile and sexually acting out. The sort of "smorgasbord" approach is the state of the art in too many of our facilities and, thankfully, in spite of that, our daughter was released.

We were also told, and this was sort of exciting, that we needed to come in for family therapy. I wish you could have heard the telephone call with the social worker at the hospital. She didn't know how many children we had, so she told us--it really was funny, people, it really was. You need a few laughs at a time like this. She called me up to quote "invite me" and when I indicated I didn't really feel the need to accept the invitation, she said that if I wanted my daughter to remain in treatment, I must accept the invitation. So I reluctantly allowed as how my husband and I were willing to go through this routine. There might be some value to it, we certainly didn't want to stand in the way of our daughter's health. And then she went on how it was really seen as facilitating to the entire well being of the family and, therefore, the entire family should attend. There was a long moment of silence when I said to her, "How large is your meeting room?" And she didn't know what to say and she asked me why. I said, "I don't know how many other families are involved, but if I come, I'll be bringing 11 other children between the ages of two and 22. Do you serve dinner? Is there sufficient time for potty breaks for the two-year old who's being trained?"

In any case, the absurdity of it all became clear. And after going to one session, we all noted that it was not so much focused on trying to help us, as it was for providing an opportunity for the social workers to keep us calm (while we were all semi-hysterical about our youngsters being in the facility), and to try to tell us with great confidence good things were happening. We didn't know ourselves because we had limited access to our own child, who was not permitted to call us. We had to go all the way to the administrator of the hospital to get past that one.

Now the ending is a fairly happy one. I'm fortunate. I live within a few miles of the National Institute of Mental Health and Georgetown University, two fine facilities. I happen to have the opportunity to talk with a lot of other experienced people who've been through it before. So much so, that when I was wondering out loud to a colleague at the office, "How long will they keep her there?", he said to me immediately, "What kind of insurance do you have?" And when I told him, he said "She'll be all better in 30 days." Amazing!

Shannon is doing well. We have the ideal situation. We have an excellent psychiatrist who is providing her with medication that created an almost miracle-like change. She is back in school. She lost all of last year. She is doing beautifully. She was accepted by three colleges and we think, maybe, hopefully, knock on wood, she's over the hump. She also has an excellent psychologist who provides her with counseling and supportive help so we think she's getting what she needs.

It cost a lot of money and it was a very difficult time. Because we were persistent and knowledgeable and pushy and really not terribly pleasant sometimes, we got what we think she needs. We still, however, live with the fear that all parents have, that at any moment this could all come undone, because we don't know why she became ill, and we don't know when she might become ill again. She's old enough and insightful enough to be fearful about that herself.

My other reason for being here is that other kind of emotionally disturbed child. You know the kind when school opens you wonder how many days before the teacher calls. That kind. I have one of those, too. He's 11. He's been thrilling people since he first went to school, which was the first minute I could find a school that would take him. He is charming at first, later gets

challenging. Kind of--persistent doesn't begin to describe the level of energy of this child. This is a youngster for whom one could say, "Well, it's easy to see what's wrong with him. He came from a terribly deprived and abused background." He was placed with us for adoption at age 3; he was developmentally delayed; he was considered semi-autistic; lots and lots of problems so that people will say to me now, "Well, I know he's really a problem, but he's so much better than he used to be. Aren't you proud of yourself?" Not really. We feel we have done a lot of battle with the school system to get what Andrew needs and Andrew only has about half of it. And each one of these battles takes us anywhere from three to nine months, depending on how far up the line we want to go. Again, we're currently pleased that we've been able to keep him in a specially designed program in the school system, but not without an enormous expenditure of time and energy. I worry about families who don't have that time and energy, who don't have an attorney husband who know the law, who don't happen to be fortunate enough to work inside the system as I do, so we know the words to say. It's hard for us to get what we needed for these two youngsters and I think it's much harder if you don't have the special opportunities we had. Nonetheless, these experiences have galvanized me. I've had such a difficult time getting what was so obviously needed help for my two children.

So what I'd like to do in the rest of my time is three things. First I'd like to reflect family experiences and you've already heard them I think. And although it's uncomfortable and I'm touched by the discomfort of some of the professionals who care a great deal about our children, and I know we don't go into mental health as a profession to make money, (well, we'd be fools if we thought we could make money in the field), I'm not terribly displeased that we have, at least, in some ways as parents helped you on the other side of the desk feel like we feel. Because that same terrible sense of being told you're not doing it right, feeling powerless, feeling unappreciated, feeling misunderstood, is how we feel as parents. And it's useful, perhaps, if only for a moment, for the other half of the team to understand on a personal basis what that's like.

I'd like to have the chance to tell you parents a little bit about some help. There is help out there. There is a family movement that I'm involved with that's working for those youngsters who are over 18 and I think there are some things we can help with. Some ideas we can impart and perhaps some practical things we can share that will move the families of younger children and adolescents forward. I'd like to encourage the continued dialogue, because where I want to get to is changing the system. Where I want to get to is advocacy, so that the workers who want to do the good work aren't fired, and the families that want to get the good help aren't in the way. What I'm really interested in is changing the entire system.

A revolution is going on in health care right now. Because we just touch one part of the system, we may not be aware that there really are enormous changes going on in all of our health care systems. And they're driven by changes in the financial mechanisms. I'm not going to bore you with any of that, but please know that this is an <u>opportunity</u>. Whenever there is change going on of a sweeping nature, there is opportunity for new voices to have impact. I'm particularly pleased to see professionals here meeting with us, not only because the dialogue is good, but because sometimes professionals are more resistant to change than they need to be. What we need is to recognize and welcome the opportunity that change brings us.

In the mental health system we have several strong changes going on right now. In terms of treatment theories, we're moving from a psychoanalytic base to a

biological base, fed by incredible research over the past ten years on the neuro-chemical underpinnings of many serious and persistent mental disorders. We're also moving in terms of the service system from a custodial model to a rehabilitative model and for us as parents that's very exciting. We need the programs that will help our young people become productive citizens. Finally, we're moving from an institutional base of services to a community base of services. And for those of us who have had to send our children away to get help, it's good news.

It's important for us to remember that whenever there is change, there is the opportunity to shape that change and to seize power. And power, as someone said earlier, is really what is needed. Power for some new people, power for those of us who buy the services, and pay for the services and so often suffer at the hands of the services. Let us start by recognizing that psychiatry and psychology currently has almost awesome power to define what is normal and what isn't. Let us also recall that psychiatry is not an exact science. You have only to read the journals to see that. As one of the earlier speakers mentioned, informed families are scaring the pants off some of those folks out there because we know that there is no exact science; there is no exact diagnosis; are no exact treatments and cures. This is a field in great transition. When there are no agreements on causes or preferred treatment methods among the various professionals and even within professions, families have to depend entirely upon the wisdom and experience of whatever clinician they happen to be referred to. Literally you can go with the same set of symptoms to different people in your community and be offered everything from individual counseling to family therapy, psychoanalysis, behavior modification, changes in diet and medication. All of these can be seen as the appropriate course of treatment for whatever is wrong with your child. There is, therefore, an enormous need for an assertive consumer voice to insist on excellence, to monitor all of these services and, because there is currently no consensus about what works, to evaluate providers and professionals and tell other families what at least the wisdom of their experience informs them is helpful.

And yet to this point, we see almost nothing in terms of children and families. There is almost no consumer voice. Very fragmented efforts. I asked myself as I came into the Alliance for the Mentally Ill and saw the enormous effort that families are making for young adult patients, I asked myself, "Why?" I think there are several important reasons that give us a line on where we want to go.

The first is, and I don't think we can underestimate this, we have in mental health a medical model. Now I've had wonderful doctors and I'm not going to put anybody down, but a medical model is a fairly closed model and it's fairly hierarchal and it's driven by the prestigious degrees, and oftentimes without meaning to, those who are particulary immersed in the medical model just don't want to hear you if you don't have the same training and background as they have. Further, we have been socialized from childhood by all the different physicans we deal with, to be good patients. After all, they went to school and they know better. We have in all our dealings with the medical world learned to see them as authorities and have accepted their wisdom almost without question. This is particularly true when we are being seen as bad parents. We at least want to be good patients.

I think there is the authority of professionals. The authority that professional structures have conferred upon them with degrees, the authority with which they address the problems, their years of experience with many, many children. You have as parents years of experience, perhaps, with only one. And

yet I think we cannot abdicate our special role as parents and allow ourselves to be pushed out. We have authority, too. We have the authority of competence, that expertise that only living with an emotionally disturbed child can give you. You heard it over and over this morning, there's nothing like walking in the shoes of someone who's going through those troubled times to give you a sense of what kind of competence and expertise that really is.

I have 12 children and it's been an inspiring and humbling experience to see both the limits and the strong measure of impact I can have on any of them. Five of them were born to me, seven of them were adopted. I've been a foster parent, as well. I have children of a variety of races and cultures, some who came to me as infants, some who came to me as adolescents. A wide range of abilities and backgrounds. No way in the world can I have predicted who would accustom themselves best to my family and who would adjust best. In some ways the ones who experienced the least amount of nurture seem to do the best in the family. It's really more of a mystery than an answer when you try to predict what families and what children will need help. So like many of you, we've tried almost everything the service system has--school-based counseling, group and individual psychotherapy, family therapy, therapeutic foster care, drug and alcohol counseling, residential treatment, even hospitalization. I feel I've really been the course in the mental health system and frankly I can't say much for how it treated me, even though I believe I'm an expert.

Like many of you, I've constantly had to bump up against the incredible arrogance and the power of a rigid system that requires you to give up control before you can get help. I really believe that sometimes parents have to fire professionals. It takes guts, but it does get a response. Sometimes you have to act out a little bit. They think you're crazy anyway. You have to assert that you won't go away. Remember, the power of the professionals is awesome and it lies in the fact that they define the problem, determine the solution, and accredit and evaluate the safety and effectiveness of the treatment. That doesn't leave a lot for the parent--the consumer of services. It seems to me that for too many of our families, the first step they take in seeking treatment for their child is too often the first step they take in losing control of their child and often of their whole family life, as well.

Now I know we have in this room professionals who care. You wouldn't be here if you didn't want to make things different. If you didn't want to be open, listening and talking with those of us who need your services. And yet a lot of times when I talk like this, I can almost hear the people in the room who are service providers saying, "Isn't that terrible? Can you imagine families experiencing that? I'm glad I'm not doing any of those things." Let me ask you to ask yourself honestly, if you're a professional in the room, what is the nature of your relationship and the relationship of your agency with families? Don't think about those wonderful policies. Don't think about that nice little booklet you give people. That wonderful packet they get when they put their child in the system. That's not where we see how you really treat families. Let us look perhaps more simply at the very words that you use--at the very ways in which you talk about families and children around the water cooler or after hours with a cup of coffee.

I hear from families who are very sensitive to these clues about their status, and they tell me that, constantly in mental health settings where they go for help, they hear two kinds of language. The first is the language of power and control. You will refer to this as professional language--technical language. But think about the impact of such language on parents who come for help. It

immediately removes their ability to understand. It creates a mystique. It sets the terms for the response. We're now talking about my child's "personality disorder." I may not know what that means. Very often we hear words like triangulation, differentiation, eco-system. Parents are not trained professionals and should not be expected to compete in understanding with those kinds of terminologies, and yet the constant use of heavily professional technical terms sets parents apart and reinforces the message "I'm educated, you're not."

There's another kind of language that we often hear in mental health settings; it's a language of judgment. We hear families and parents referred to as neurotic, the ever-present dysfunctional, overinvolved, (I'm certain I'm one of those), pathogenic, enmeshed, and my God, are we enmeshed. And then you hear, (often many families sadly come to this), treatment-resistant. My God, who wouldn't be? Who wouldn't be? When families are handled and treated instead of supported, they will be resistant, I can tell you for sure.

What do families want? I don't think it's useful to spend more time telling you what families don't like. I think by now you all have got the message. What do families want? Again, I have the opportunity to talk to families who are veterans of this system. There are some clear themes. Families, you know it's interesting. Although they're the ones seeking help and they are sometimes the ones who are receiving help, they are rarely seen as agents of help and almost never are they asked to make recommendations about what they think would help! But families do talk back and so they told us what they think is most useful in forging a partnership with professionals.

The first thing they want from you is the obvious one and yet the most elusive. They want respect and they want dignity. They want you to know that their expertise is real and just as vital to the health of the client, their child, as your expertise. You see the child one hour a week, maybe two hours a week, or maybe an hour a day. Parents see that child 24 hours a day, seven days a week, as often as possible, often under great stress. So the first thing in establishing an alliance or a partnership is to start with the basis that all peer relationships start with, respect. Respect for my knowledge.

Families want information. They want choices. Oftentimes families are considered unable to assimilate the information, the information will be damaging to them, they're not ready to hear the information, or we're not sure of the information so we'd better not say anything. I loved the person this morning who said that one of the best things we can do for families is to say to them honestly, "I don't know either." This opens all kinds of doors of communication and because this is a field in transition, there is such a lack of knowledge, we are all aware that you don't have all the answers, and it's wonderfully supportive for you to say that honestly.

Families want involvement and they want practical skills. It's nice to sit down and look at that 42-page treatment plan and have it all walked through and signed off and up one side and who's going to pay and all that. It's more useful yet to get some basic help in coping day to day. Coping with the child and his behaviors, coping with the strain on the marriage, coping with the strain on yourself, coping with the strain on the other youngsters. Not to mention coping with the system itself. The thing that most people come to us most frequently for is practical help. "What do I do when my child throws a chair out the window?" "How do I talk to the police when he comes to take my child away?" "What can I get from the residential facility? Do I have to let them only see my child once a month?" That kind of help is very important.

Families are looking for support and they're looking for respite. You know, we have conferences on burn-out for professionals, and yet parents are expected to perservere forever. Parents need respite care, much deserved respite care. Quite frankly, they cannot continue very long without respite care.

Families are looking for follow-up and linkage between systems. It's a scandal what we don't have between our systems. It's one of the reasons that children--they don't fall through cracks--they fall through canyons. It's incredible. Families need crisis help. Crisis becomes a way of life for too many of us and yet we can't count on the same team that helped us last time being available this time. Oftentimes families tell me that they don't have anyone to call at a time of real need and it's interesting how these needs occur after 5 and on Saturday and Sunday. It's amazing.

Families want to be empowered in this system as consumers and I think family advocacy is what will make the systems serve the children we're all concerned about. I really do believe the old Washington adage that "things don't just happen, they are made to happen." And I also believe that I'm not paying anybody to care about my child. That's my job. I'm paying people to perform for my child. That's what they're paid for. I think it's important for advocacy to be very clear in its goals. I will not be happy with the mental health system and how it relates to children until it becomes the kind of priority for other people that it is for me. Until it becomes so important to our politicians that it's not politically viable to ignore my phone call. Until we have a conference and don't have room enough to put all the people. Until we have TV cameras here covering it because it's a major event. Until we have governors clamoring to be speaking so that I can't get on the program anymore. Then I'll think we've gotten somewhere in empowering families.

Emotional and mental illnesses, it has been said, are the most solitary of diseases for those who suffer from them and the most social of illnesses for those who bear their consequences. This leads me into perhaps the most difficult barrier of all. The barrier of stigma. All of you know how hard you resisted giving your child the label of "emotionally disturbed" or "mentally ill." The label is a prison. It's a prison for the child and often it's a prison for the family. And too often that prison has been constructed by some of the very professionals who are there to help us. I will be delighted to see the day when professionals stand up here and say "You know, families didn't cause these emotional disorders. They're not the reason that these children are so disturbed." Too often, too much in the literature, in the conversations with professionals reveals their continuing belief that somehow, somewhere in that family interaction, in that poor bonding, in that difficult communication, or that repressive environment, the family created this terrible child and will never be able to help the child until the family is different. I don't believe that and I don't think science any longer supports it. That is not to say families don't have a responsibility to help create an environment that will give the child less stress and more support. But we will engage families first when we free them from guilt and blame.

I go to a lot of PTA meetings, you can imagine how many PTA meetings I go to. And over the course of time I have seen parents stand up and make beautiful statements about "I want special services for my hearing impaired child." "I want special services for my retarded child." "I want a special class for my physically handicapped child." "I want a ramp for my child in a wheelchair." Never have I seen a parent stand up in a PTA meeting and say "I want to talk about services for my severely emotionally disturbed child." If any of you out

there have done it, it's a fascinating experience. I just did it about two months ago. And the room was so silent. It was like standing up and saying "I'm a bad parent. I can't do it right."

People will simply never be able to take us seriously until we all stand up and say, "I have a child with a serious emotional handicap and it's the problem of everyone in this community." We have to get out of that prison, regardless of how it was created. We have to get out of that prison because that's the way our child will get help. The first place to go to get out of that prison is a family support group and I know some of you here are involved in family support groups. I invite any of you who are not to talk with me about linking up with your local chapter of the Alliance for the Mentally Ill.

I've spent a lot of time talking to you and I haven't told you much about our organization. Let me describe it to you very briefly. We were founded in 1979. There were 80 groups around the country, most of them small, fewer than 300 people got together in Madison, Wisconsin. These were people who were in many cases graduates of the child system, school system, and now their young person was 18 or 20 and wasn't getting over his transition problem and wasn't becoming independent and had a serious long-term illness. Today we have 598 local affiliates. We have state affiliates in 39 states. We have 30,000 families. We are gaining local support groups at the rate of one every 36 hours. Clearly, we're meeting a need. Until we came along, all families with a mental or emotional problem were hidden in the closet. Nobody told anybody and everybody was alone. Our movement has grown rapidly because we've been very clear about what we want.

There are four building blocks to our organization. The first is support. Emotional support which everybody needs because there is no effective cure for these disorders. They may get better with time, certain things may help, but the people we're dealing with will have a long-term handicap at some level. So we see support as the heartbeat of our movement. I encourage everybody here to check out their local group. Whether you go to one meeting and find out what these folks think about the various service providers and get some consumer feedback, or join and stay for as long as you need the help. It's a very effective way to feel part of something that can offer hope.

We're very big on education-- educating ourselves so that we can be peers with those who are providing services, educating the public so it begins to regard our mentally ill and emotionally disturbed relatives as people who count. As people who should be understood. As people who should not be avoided, but who should be welcomed and encouraged into their full potential. We're also very interested in helping parents so we've developed a coping course so that families who want to learn how to do a better job of coping, not curing, just living with a long-term disorder can get the practical advice only families can give.

Advocacy is where all of us want to get. Advocacy allows us to use our frustration and despair in a positive way to bring our personal testimony to whatever legislative body so that people can hear what the mentally ill and emotionally disturbed in our country are really like and what they need. Over the years we've fought hard for a community support system because we only hide away what we're ashamed of and we're not ashamed of our children. We fought hard to keep funding for the CASSP programs going because we know what pain you families are going through. We just graduated ourselves. We're looking for practical things like housing and jobs and we're looking for increased research opportunities because we want to unlock the mysteries that caused our family member, our

children, to be so sick.

We know this is going to take time, but then again we know how much time we've already spent. And we believe in working hard for our own children. We believe that work is love made visible. We intend to work as long as it takes until we get to the point where we have some answers and where we have some help. I hope out of this conference, we will not only develop a greater understanding of each other, a greater respect for each other's roles, but that we'll also be able to see some action agendas because sitting around talking to each other really is like preaching to the choir. It's that vast public out there--it's those people who sit and make decisions and don't know we're here and so don't have to be worried about what we think. We have to find a way to create not only a parent support network which is crucial, but a parent advocacy network which is how we'll get that cathedral built.

My organization is planning a two-day meeting attached to its national meeting in '87. We have a conference every year that brings about 2,000 families out--all families--and we'll be having a two-day meeting especially for families of children and adolescents in September 1987. I know I've talked a long time but I have a lot of feelings about this topic.

Let me just close by restating as I did up front some of what I believe and some of why I came all the way from Washington to meet with you folks. I believe in the strength of families and I believe in the power of love. And I believe in the family movement and I believe in the value of caring professionals. I believe in partnership and the catalytic role all of us in this room must play in creating a partnership. And I believe we must do better, much better, in our system than we have in the past because so much of what's been done in the past has been so very poor. But most of all I believe in Shannon and Andrew and all of your children. I know what hopes and dreams you have for them and I know how much you want to make those dreams come true.

To professionals I would say, work with families as allies or get out of the way, because families are going to make it happen. Families are no longer going to be invisible and silent. No longer are families going to accept a passive role defined for them by others. I hope all of us can leave here as allies and I hope in the course of all the openness and sharing that we'll develop some love between us. Because as I stated at the beginning, love is a verb and we've got a lot to do.

PANEL 2: OVERCOMING BARRIERS TO PARENT-PROFESSIONAL COLLABORATION

SAM CHAN

Dr. Chan, a licensed clinical psychologist, is the Director of Training in Psychology at the University Affiliated Program, Children's Hospital of Los Angeles. He is also the Chairperson of the governor-appointed Board of Directors of Protection and Advocacy, Inc. for the State of California and has previously served as board chairperson of several community agencies and organizations. Throughout the past ten years, Dr. Chan has been a mental health consultant to schools, regional centers for the developmentally disabled, Head Start and other early childhood education programs. During this period, he has developed and implemented numerous parent education programs and currently directs a statewide parent-professional training-of-trainers project which serves Asian, Black, and Latino populations.

When the gentleman asked the question about how many are aware of legislation 94-142, I asked a similar question, how many are aware of the 98-199 amendment to that particular piece of legislation? That legislation is what really originated our project. Those amendments were set up through the Department of Education and basically authorized grant awards to nonprofit organizations for the purpose of providing training and information to parents of handicapped children. The main impetus of those programs is to enhance parents' abilities to work more effectively with professionals in promoting their children's educations. A particular concern was for members of underserved populations--which is kind of a euphemism in our field--but which particularly relates to minorities. The underserved in California happen to be, as I mentioned in a workshop yesterday, emerging as the majority population in our state.

We set about, through the auspices of our state's protection and advocacy system, to apply for these funds and, in 1984, received a grant to initiate the Multicultural Training-of-Trainers Project. I brought along a paper which provides a summary overview and a report of our results in the past year, as well as some pamphlets which you are welcome to have. Today, I just want to share real briefly some of the basic aspects of our model of training and what some of our findings have been.

The philosophical underpinnings of the project have to do with three essential components. First is the primary emphasis on parent empowerment. Second is the notion of parent-professional collaboration. We are striving toward that goal and to then develop culturally and linguistically appropriate models of parent education and training. We have a very strong ethnic parent advocacy orientation, in terms of moving in that direction with the collaboration of ethnic professionals.

We look at a number of different goals that are mandated by that legislation for all of the parent training centers throughout the country. They include providing parents with information to understand the nature of their child's disability, supportive resources that they can utilize, ways to communicate effectively with professionals, how to understand what the resources and the systems are and how to deal with the systems out in the community, and then their basic rights and responsibilities as parents.

We develop a model that allows parents to initially collaborate with team members-providers from their respective agencies and communities from the same

ethnic background who undergo an intensive three day training experience to learn group process and leadership skills. This then forms the cadre of parents who have been identified initially from parents from throughout the community as potential leaders who can then go on to establish community, and then their basic rights and responsibilities as parents.

During the first year of our project, we had a parent training project which focused primarily on parents in the community. They received more direct, individualized types of training. During the first year of the project we went from serving 70 parents to serving 240 parents. The spread effect of training trainers is obvious in terms of the critical need to train ethnic parents as resource people to work with other parents, as opposed to relying exclusively upon professionals for that purpose.

From the standpoint of our model, the notion of parents and professionals collaborating in a direct manner to implement and be responsible for their own community based training is a necessary one. The notion of team responsibility isn't just a matter of training. They actually have a joint responsibility for implementing the project for other parents.

When parents do begin the process of working in their own local communities, we've found that the benefits of not only an educational and training focus, but also the evolution of group support within each of those parent based community programs, is really profound in terms of its impact on the other parents. The notion that a parent is the one running and leading that group is probably one of the most important factors in terms of how other parents are motivated to continue coming and receive the benefits of that training.

In our first year, we served Chinese parents in the Bay Area, Korean and Latino parents in Los Angeles, and this year we are working with Chinese parents in Los Angeles, Vietnamese in Los Angeles and San Diego and the urban black population in Los Angeles.

Ruby Brown has joined us for the last two days and was present in our workshop yesterday. She is one of our parent trainers and has a lot to say about her experience.

In our first year we had twenty different parent trainers and providers who formed teams all throughout these areas and ended up, as I said, serving about 240 parents. The overall outcomes, in terms of what was gained and the knowledge by both the parents who came to these workshops, as well as the parent trainers themselves, I think, is summarized in the report. Sometimes we look at a lot of different ways to evaluate the effectiveness of programs in terms of data and outcome measures and so forth, but again, I think through their testimonials and what parents really say afterwards, makes the most difference in terms of how the project is viewed in the community.

When we look at some of the comments that were made by parents who had participated, each of them really appreciated and expressed how valuable it was to learn and communicate with other parents, but also to communicate with ethnic professionals who translated and made available for the first times in many of their experiences in their own languages. It gave them a sense of both learning how to assert themselves and communicate in the context of a workshop that could then generalize later to their own settings, IEP meetings and programs which required them to deal with other professionals. They learned the skills of communication within those workshops.

The parent trainers themselves, I felt, also gained increasing self-confidence over time in terms of how they are organized and facilitate development of a group and the development of leadership skills in other parents. I think they were very gratified that they started out at a fairly insecure place and then organized something that would promote this kind of growth in other parents.

The kinds of things that we see in terms of comments from the parent trainers are statements like, "If I behave like a leader, people will treat me as one." I think that this is the message that parents gain, that the key elements of leadership that they acquire have to do with the notion of developing a vision of what they hope to accomplish for their group, the notion of heart or commitment, the ability to take on challenges and the guts to assert oneself and fight battles for their convictions and the notion of sensitivity.

They had to learn a great deal of sensitivity in exploring the needs of parents of children with other kinds of conditions and how to draw those parents out into a workshop that they were implementing. The other comments that came from providers, in terms of notions of what they had learned collaborating with parents, were statements like "I learned to treat parents like people, instead of clients." Many of them had to undergo a process of change to take on differing perceptions.

Providers from various agencies also recognize the importance of raising the consciousness of their home agencies to support groups, such as they had been a part of developing, and to insure that these groups would have continued support in those communities. They also learned that they have to work very closely with other providers to break down some of the attitudes and support the fact that parent groups should, in fact, be run and conducted by parents if they are to be truly effective, with the support of professionals.

The final statements that the parents themselves made were along the lines that they recognized the need to defer to professionals for certain areas of expertise, but also to expect that they will always have to deal with problems, and that together they can work and learn to solve problems in a collaborative manner.

I think the final outcome of our project now is to move to varying levels of training where, beyond training trainers to develop community based groups, we will be actively working towards a more formal leadership training component, where those parents who emerged as trainers in our various programs will then go on to help develop coalitions of parents for other ethnic minorities to impact legislative developments in the state and work at high levels of involvement that will impact whole systems in addition to the community based experience.

We have an opportunity next week in our second annual state parent-professional conference to have a four hour workshop to deal exclusively with the MTOT project. We will be showing a series of videotapes and sharing materials and so forth. Many of you will obviously be unable to attend that. I welcome you to contact me in the future for any kind of reference materials or ideas. I think that what started out as a project focusing primarily upon minorities, we are proud to say, has impact upon mainstream parents and a lot of other programs throughout the country. We are the only project of its kind that was funded and we will see if we survive for another three years. Thank you.

DAGMAR PLENK

Dagmar Plenk is the CASSP Director for Wisconsin. She was formerly a developmental disabilities consultant, working with parent advocacy and professional advocacy organizations on behalf of children with disabilities. Ms. Plenk worked with children and their families to develop community service plans based on individualized needs assessments. As a PASS Trainer she coordinated systems evaluations in the area of services to children with disabilities.

I think I might be disappointing you in your expectations. When Barbara Friesen first invited me to be on this panel about overcoming barriers to parent-professional relationships, I prepared this nice little talk about some of the major barriers and how to dismantle them. My nice little talk was being dismantled within the first hour of this conference yesterday. When Cindy, Glenda and Richard spoke to us and said exactly some of the things that I was going to say, I thought, "Well, so much for that. Oh my God, what am I going to talk about tomorrow?"

Well, last night I had the very good fortune to hang out with a bunch of wonderful women who talked about their children. Their children wear a label of differentness. I told them that my astute and sensitive little talk for today had already been given by people who have far more knowledge and experience than I and that I was at a loss about what I was going to say. I was panicking and whining and all of that.

One of the parents in the group said to me, "Well, you can talk about the fact that we are <u>all</u> parents of handicapped or emotionally disturbed children." Everyone's child in this room is yours and mine, too. <u>Everyone's</u> child is yours and mine.

That means that when I go out and do my thing as a good bureaucrat in the State of Wisconsin, I write social policy with Denalee's Aaron in mind. I go to planning meetings knowing about Nancy's Adam. And when we network--I don't know how we use a noun as a verb--when I network with other agencies, I remember Linda's Brian. When I go and talk to my legislators and tell them about the children whom I know in my home state and who need our sensitivity and respect and competence, I can say, "And there is also Josh in Pennsylvania, Tommy in Kansas, Andrew in Washington, D.C., and they are our children, too.

LINDA SCHARNBERGER

Linda Scharnberger received her Master of Science in Social Work, specializing in mental health, from the University of Louisville's Kent School of Social Work in 1978. She has had over ten years of experience in children's services in a variety of settings, including residential treatment facilities, a child psychiatric hospital, and a shelter for battered women and their children. From October 1985 to May 1986 she worked for AMI of Wisconsin as the Director of the Child Advocacy Project, a statewide undertaking seeking to organize the families of emotionally disturbed children into community based support and advocacy groups.

I, too, felt that many of the things I wanted to say were covered very admirably yesterday by almost everybody who spoke. So I asked Phyllis, "What, really, am I supposed to say that's different?" She said, "Well, people want to know what you are doing in Wisconsin." So I'll tell you a little bit about this and try

to keep my remarks brief as well. Before I do, I want to say this: I am finding the work I am doing with the Child Advocacy Project to be personally and professionally redeeming and balancing. So I'll tell you what I'm doing.

The project is a cooperative project between Wisconsin CASSP--and Dagmar and I are working very closely together on this throughout the state--and the Wisconsin Alliance for the Mentally Ill. You know a little bit about AMI from hearing Laurie Flynn talk yesterday.

The project has three goals. One is to organize the families of emotionally disturbed children and youth into community based support groups which would be similar to the groups that Cindy Boatman, Glenda Fine and Richard Donner talked about yesterday. The second goal is to organize these groups into a statewide network which we've decided to call "We Can," which stands for Wisconsin Child Advocacy Network. We thought that sounds pretty upbeat and it sounds like we are going to accomplish something, so I hope that we do. The third goal, hopefully using this network of support groups, is to advocate for comprehensive, community based services for this population. We would like to see a continuum of services in Wisconsin that goes from the most restrictive, where that is necessary, to the least restrictive. In Wisconsin, there is an awful lot of work to be done, because we don't seem to have much in the way of least restrictive. That's one thing we would like to work on.

I've only been working on the project since October. In seven months we have, at this point, four communities where we have groups going. Two of the groups were in existence before I got started on the project. One of the groups was a group that was related to the Alliance for the Mentally Ill movement in Milwaukee. The group leader there is a woman who is the mother of a manic-depressive thirty year old woman. That child of her's is not able to raise her own children, so this mother is now raising five disturbed grandchildren. She's also a treatment foster parent herself. She is the co-leader of the Milwaukee group along with a professional who is a child therapist at a treatment facility and he is also the brother of a mentally ill sibling.

The group in Rock County, which was also meeting before the start of this project, was another group where there is professional collaboration. It was meeting parents and professionals from the special ed program of one of the school systems down there. They have done something wonderful. They have made a couple of videotapes for parents and for professionals to show what it's like to live with an ED child. The goal of these tapes is to provide community education. It's possible that we may be using those with CASSP around the state to do some education.

The other two groups are one that I started in the county I live in, and one that was started in another county by another sibling of a mentally ill person. These two groups are working in their communities on some tasks that I think parents will find interesting. The parents in these parent groups are developing a list of resources for their communities that they want to share with other parents in the community--where you can take your child for this and that kind of treatment and this and that kind of help, and who's good and who's not good.

They are also working on a manual of how to go and do the things that you need to do as a parent of an emotionally disturbed child. How to go into juvenile court and get your courage up and talk to the judge. How to go and talk to that social worker. This is something that the parents came up with themselves.

They are working on this themselves with collaboration from professionals where it is needed.

They've come to the professional community and said, "Can you help us get these materials together and we will put them together in a manual?" We are also doing that on a statewide basis through our CASSP project as well. We're hoping to come out with some specific community lists and manuals through the groups and some statewide manuals through the collaboration of parents and CASSP as well. So that's what we're doing in Wisconsin. I have two minutes left. I don't think I need them. Thank you very much.

MARSHA GOULD

Marsha Gould, MSW, is Executive Director of the Colorado Children's Campaign, a non-profit, multi-issue child advocacy and public education organization. Previously, she taught at the University of Denver Graduate School of Social Work and has been in private social work practice with children, adolescents and their families, a medical school social worker, a field instructor and an adoption supervisor. She was Director of the Child Welfare Project, and Administrative Coordinator of Children and Youth, a certificate program, at the University of Denver School of Social Work. She has done training, research and grant writing. Ms. Gould received her Master of Social Work degree from Columbia University in New York. She is a doctoral student in the Graduate School of Social Work at Denver University and anticipates completion in 1987.

I probably have the dubious distinction of being the only presenter who was not invited, but who called up and invited herself. I think it was Dick Engstrom I talked to. I said, "You need me here because I am a professional who has worked for 20 years with children and families. I am also the parent of a child whom the schools consider emotionally disturbed. I have just always thought he is a pain in the butt. And, I am a trainer and teacher of professionals who have tried to come from the posture of a non-parent blame model, that I will tell you about. And I am an advocate for systems change on behalf of kids. A range of issues. I will also talk about another option for you--the multi-issue state-based advocacy organization that looks at a range of issues that affect kids' lives and many systems that affect kids' lives.

Let me say, first of all, the posture I take with respect to why parents and professionals have not worked well together. My own feeling is that it has to do with--and I think it was mentioned yesterday--the theory that professionals are taught about why children become emotionally disturbed. The position that I've taken has earned me a great deal of criticism from my colleagues. I suspect it will set well with many of you in the audience. I hope so. Let me just tell you about it, because I'm not just talking about the obstacles. I want to suggest an alternative.

As people, we have been trying to find the answer to the question, "Why?" for many years. The cavemen wanted to know why thunder and lightning occurred and came up with answers. In terms of emotional disturbance or mental illness, the answer to the question, "Why?" historically was that people were possessed by demons. I think that, in some sense, we've been operating on that same premise.

One of the most powerful influences in professional training has been psychoanalytic theory, which is a very linear approach to why children have emotional disturbance or why any of us do, I suppose. It says that early life experiences in your childhood directly affect adulthood. It says that children

are the product of parents' own poor parenting or internal conflicts, or perhaps marital and family conflicts. That's why kids have the problems they do.

I might say, by the way, that I really don't use the term--or find it useful--emotional disturbance. I think kids are either troubled or troublesome. All of the kids we talk about fit in one of those two categories. Now that posture, it seems to me, has led us to a number of terms that are really interesting when you look at them. Somebody coined the phrase, "mal de mere." It's called "sickness of the mother." If you want to understand why a kid is the way he is, look at his mother. There were the schizophrenogenic mothers. Those were the mothers powerful enough to make kids hear voices and have strange moods. Then there was the refrigerator mother who caused autism. Then there was the overprotective, if you will, Jewish, mother which crosses all ethnic groups. By the way, the refrigerator mother, I think, was very interesting. When we thought kids who were autistic were caused by a person who was very aloof and distant, in reality what we found was that perhaps that mother became aloof and distant, not only because she had a troubling child, but because she also dealt with professionals who were critical.

Let me just say, I accepted all those theories until my second child was born. I was very comfortable with those approaches since my first child was easy. My second child was difficult from the time he could move. I had to then find some explanation. Luckily, I was a doctoral student, so I went in search of a new theory.

The theory was a reciprocal interactive model of child development. It basically said, "Kids are unique at birth. Kids bring their own characteristics. Those characteristics affect the kind of behavior that they elicit from parents and parents deal with every kid differently."

Many of you are shaking your heads. This is something every parent has known, but somehow professionals couldn't quite figure out for awhile. All I would say about that is simply that when you have a reciprocal interactive model which goes like this, it's not possible to lay blame because there is no beginning or end, but there is a difference between responsibility and causality. Parents are responsible for their behavior, for their expectations, for their responses to kids. Parents can alter that. Little kids can't. But it isn't the same as saying to a parent, "But you caused that kid's disturbance." It says, "You have a kid who is troublesome or troubling and, in that instance, you need to alter what you do."

Let me switch to a lot of things here and simply say that there are a number of things that we can do. From the point of view of professionals, we can adopt an interactive model. We can also watch some of our language, it seems to me. We use a great deal of perjorative language as parents. We talk about multi-problem and dysfunctional families. It seems to me that, in reality, families are multi-stressed, multi-systemed and have limited resources. If we look at the situation that way, there is a great deal that we can do in joining together. As professionals, as I said, we can move to an interactive model. As parents, we can reject the notion that we are the cause of problems and we can advocate for our children. By the way, when you do that, if you happen to have an aggressive child like I do, you know when you leave, people say, "Aha, we know how that kid got to be that way," but it doesn't matter.

Also, let me say to you, parents, I don't think you should fight professionals. I think you should assume that people in systems wish to do well also, and join

with them. There is a very important reason for that in terms of a policy level. If you join together first of all on a range of issues--health care, poverty, kids in the welfare system, in the foster care system--you have much more power. You have power in numbers and in emotionality. You have feelings.

Professionals, though, have the credibility of their degree and that's useful to you. By the way, you also need each other, because professionals can't speak out for more services and programs. They look to be self-serving. They look as though they are tryng to keep their jobs and, in part, they are. You also can't speak out all by yourself because people think you are just trying to do it because you've got guilt. Join together, I would say to you. Don't let this divide and conquer economy take over. Join together and we can win.

STANLEY ROSE

Stanley Rose, MSW, graduated in 1982 from the Graduate School of Social Work, University of Washington. He obtained his bachelor's degree in human services from Metro State College, Denver, Colorado, in 1978 while employed at the Veterans Administration Hospital as a Drug/Alcohol Outreach Worker. Mr. Rose counseled families of substance abusers from 1972-1978. He retired from the U.S. Air Force in 1975 after 20 years' military duty. He has worked with individuals and families in the area of physical and emotional handicaps at Goodwill Industries, Tacoma, Washington, from 1979-1980. Mr. Rose is presently employed as Exceptional Family Member Coordinator at the Army Community Services, Ft. Lewis, Washington, where he assists individuals with physical or emotional disabilities and their families.

How many minutes do I have? Just pull my coattail when I'm getting close. I would like to just share with you today some of the things that are going on at Fort Lewis. Before I do that, all of the people from Washington, would you please stand? All right, I just want you to observe that. Thank you very much. Can we give them a hand? I had a real selfish reason for this.

We have approximately five to six hundred families out of a population of approximately 25,000 that are being serviced for physical or emotional disabilities. This program is called the Exceptional Family Member Program. It includes not only children, but any adult family member that may have a disability. Now, what are some of the things that are going on there? I had a lot of notes, but I'm going to throw them away for the time being and just talk from the hip.

One of the things that is happening is that we attempt to network with the services that are available in our local communities. At least once a year I have a chance to come down here to Portland and Vancouver because we have satellite units at Vancouver Barracks. A limited number of families are there. We have a responsibility to report that back to our bosses. I won't go into all of those things because we get into too much Army jargon.

The idea is to identify health related services that are available to families that may be coming into Fort Lewis for the very first time. After they come here for the very first time, they may have the fortune or misfortune to come back a second or third time! They are then aware of the services that are available.

We come out to the individuals whom you've just seen stand up here. They are some of the players. They are running a lot of those programs. They are

responsible for getting information to me so that I can go back and design a list of services that I can hand out to my family member and say, "Hey, look, these are some of the things that are available in your local area, within a 40 or 45 mile radius." That's one of the things that we do at this particular institution.

The Exceptional Family Member Program is not just for Fort Lewis. It is an Army program. The Air Force has what they call the Children Have A Potential Program--the CHAP Program. They should work the same way.

I was talking to a Coast Guard gentlemen back there who is up in Adak or Juneau, Alaska and we talked this morning about attitudes. That was mentioned here yesterday--attitudes and communication. I think those are two important things we have to recognize when we are working within the system. Having spent 20 years in that uniform myself, I have a way that I can deal with some of those people who come in with a fear of change. That fear is not needed. Then you can sell some of the commanders on why they do need the program. But the main thing is that we're working for you, the parents. Or, we're working for that handicapped family member who needs a service or who needs to come in. So, those are the things that are happening with me.

Now, we have a parent support group called the Special Children in America. They meet once a month. They have other functions. They bring in speakers from all over to talk on various disabilities. We also have a special children's Christmas party which is basically designed for social interaction so that our children can interact with siblings and other children.

We also have the Washington State Special Olympics. I'm responsible for coordinating the volunteers for that. That's coming up May 30, 31 and the 1st of June for those of you who may be in the area. With the tightness of security on the gates, please get your names in if you are planning to attend.

One of the other things that happens is that we do five-week parent workshops where we talk about Public Law 94-142. We talk about the regulations that govern the schools overseas. We hand them the handbook that I brought with me that some of you have out there--the parent handbook. You look through that and you will see some of the other services that happen through our office. With that, I think I am just about ready to be pulled. Thank you very much.

OBSTACLES TO PARENT-PROFESSIONAL COLLABORATION

Worksheet

The purpose of this work session is to identify some of the important issues that may make it difficult for parents and professionals to work effectively together. In some cases these obstacles may lie in the relationship between professional service providers and a family concerned about a particular child (case level). Other barriers may be related to such things as agency policies, eligibility requirements, funding regulations, and so on (system level). Other issues may fit into neither category.

WORK SESSION A: Parent and Professional Sub-groups (Monday, 1:30 p.m., 45 minutes).

CASE LEVEL ISSUES EXAMPLES

___ Parent Subgroup ___ Professional Subgroup

SYSTEM LEVEL ISSUES EXAMPLES

OTHER ISSUES EXAMPLES

Recommendations for _____Professionals _____Parents

1.

2.

3.

4.

5.

WORK SESSION B: Parent-Professional Session (45 minutes)

ISSUES EXAMPLES

CASE LEVEL

SYSTEM LEVEL

OTHERS

Joint Recommendations:

1.

2.

3.

4.

5.

OVERCOMING BARRIERS TO PARENT-PROFESSIONAL COLLABORATION

Worksheet

The purpose of this work session is to identify several important issues that are specific to each state (or community) and begin to develop strategies for promoting effective parent-professional collaboration

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WORK SESSION C: State Delegations Meet Together (Tuesday a.m.; 1 hr., 15 minutes)

OBSTACLES	STRATEGIES

OVERCOMING BARRIERS TO PARENT-PROFESSIONAL COLLABORATION

WORK SESSION D: State Delegations Continue (Tuesday p.m.; 1 hour, 15 minutes)

FOCUS:

CAN DO IMMEDIATELY WHO WILL DO IT?

WANT TO DO BUT NEED FURTHER INFORMATION, RESOURCES, ETC.

What is needed?

How can we get what we need?

ACTION PLANS

ALASKA

GOALS:

1. Identification of child and family needs in Alaska

2. Policy makers need to listen to the needs of the people working at the local level.

3. Parents and professionals need to work together in creating and maintaining quality programs that meet the needs of children and young adults.

Strategies:

What needs to be done and by whom:

1. Personal contacts to get individuals involved in parent meetings and advocacy groups.

2. Identify specific needs of native families:

   a. Contact John Vandenberg, Pam Colorado and Cathy Stratty (Parent Aid in Juneau developing a program for Native Parents, run by Native Parents) (done by Ralph)

   b. Plan to put a parent group together in Anchorage and Fairbanks area (done by Shirley and Julie)

   c. Help adolescents start a peer support group (done by Julie)

3. Educate the lay person about the legislative process to increase effectiveness in working with legislators (State and federal level)

   a. Involvement with Alaska Action for Children, working with Glenn Ray from Kellog Foundation to try to work out implementing the program in Juneau (done by Bruce McIntosh)

   b. Contact legislators (done by Ray Lemons)

4. Evaluate program's effectiveness. (Done by joint effort of professional and parent)

   a. Create a video tape based on this conference to use with Mental Health Providers, educators, AMI groups, etc. to try to coordinate providers, agencies and parents (done by Ralph, Ray and Bernadette).

   b. This model could be replicated in Anchorage and Fairbanks. Talk to Thelma Langdon from Anchorage about the idea (done by Ralph).

   c. Put Ray Lemons on Ralph Coleman's Board of Directors.

ARIZONA

GOAL:

Develop a cobweb of advocacy groups in Arizona to begin to address the needs of these special children.

Strategies (can do immediately):

What needs to be done and by whom:

1. Hook up existing advocacy groups in the state (done by delegation to the conference).

2. Use these groups as a steering committee to address obstacles and initiate strategies. Utilize existing resources in this state.

Strategies (longer term):

What needs to be done:

1. Locate more information about successful programs and efforts in other states. Contact presentors at this conference who can provide assistance to us. Contact CASSP office for assistance.

2. Technical assistance from representatives of successful programs and CASSP.

3. Develop and fund advocate position, which is independent of State agencies and providers:

   a. advocate for children
   b. provide information
   c. provide techical assistance to anyone
   d. monitor programs and services
   e. educate public through public relations

4. Develop statewide information clearinghouse for special needs children including computerized system that would interface with other State and national systems.

5. Develop a comprehensive statewide case management system for special needs children;

6. Develop programs which adequately address problems of minority children with special needs.

7. Develop legislation to mandate school administrators and providers to adequately monitor PL 94-142.

ARIZONA (Continued)

Arizona Obstacles:

1. Lack of inter-agency collaboration;
2. Duplication of efforts;
3. No resource directory of services;
4. Lack of teacher guidelines for identification of children;
5. Lack of comprehensive evaluation to diagnose the educational needs of special children;
6. State not providing monitoring system of evaluation system;
7. State Department of Ed's interpretation of PL 94-142;
8. School system legal obligation regarding PL 94-142;
9. Lack of advocate groups for special needs children;
10. Lack of advocate coordination efforts - districts and state-wide;
11. Lack of public awareness regarding the needs of special needs children, in legislature, administrators, providers, parents and general public;
12. Lack of educational services for parents and providers, separate and together;
13. Lack of continuum of services;
14. Lack of case management of services;
15. Failure to adequately address the needs of ethnic minority children, culturally, linguistically and programmatically;

COLORADO

GOAL:

Get Colorado people together for: dialoguing, linking, planning, advocacy, commitment to parent/professional partnership.

Strategies:

1. Plan meeting by June 1st;
2. Re-contact each other by May 9;
3. People committed to specific tasks towards planning this meeting;
4. Return and meet with people who were at the conference and others to plan to replicate conference on a statewide basis;
5. Promote ideas of advocacy organizations.

HAWAII

Hawaii established a parent/professional collaboration group at this conference.

GOALS:

1. Increase community awareness, provide a central information point, promote positive attitudes.

2. Formation of parent support groups.

Strategies:

What needs to be done:

1. Conduct a statewide conference, along the format of the Portland conference, focusing on parent/professional collaboration and on emotionally disturbed children.

2. Give focus to core group.

3. Form parent support groups.

4. Use topics from Portland conference.

Hawaii Obstacles:

1. Parents are threatening to professionals;

2. Parents see mental health practitioners as collaborators with the Department of Education;

3. Lack of standardized procedures within school districts;

4. Community/public prejudice against emotionally disturbed children, parents feel harassed by community;

5. Professionals lack awareness of available services and what those services entail;

6. Lack of funding, lack of trained personnel;

7. No one listens to the child;

8. Time constraints;

9. Impact of agency policies;

10. Lack of long term facilities/other resources;

HAWAII (Continued)

11. Professionals don't listen to parents, don't hear the intensity of their feelings;

12. Parents feel inadequate, guilty, lack self-esteem;

13. Lack of trust by parents for professionals and system;

14. Lack of respect for child by educators;

15. Geography of Hawaii;

16. Emotional needs of parents are not met;

17. Lack of parent/professional organization.

IDAHO

GOAL:

Public and professional awareness, parent support, development of home based services

Strategies (can do immediately):

What needs to be done and by whom:

1. Develop ways for getting a course on parent (natural, foster and adoptive) education at Boise State University, based on successful model used for tackling substance abuse (Marilyn Dorman, Roseanne Harden).

2. Contact State Bar Association after new commitment law is passed. Develop workshop for lawyers about new law and how to present to parents in a humane way (Roseanne Harden).

3. Hold a conference in Fall for parents and professionals (Marilyn Sword - CASSP).

4. Publish a newsletter for CASSP (Marilyn Sword, CASSP).

5. Develop a training program for parents, statewide (Marilyn Sword).

6. Write a parents' manual (Marilyn Sword).

7. Design a form to determine interest in:

   a. parenting groups
   b. legislative efforts
   c. newsletter (Pam Olsen and Marilyn Sword)
   d. how to tackle confidentiality concerns (Pam Olsen and Marilyn Sword)

8. Send information on community action and organization to parents (Marilyn Sword).

9. Form local support groups (Carol Taylor, Lynn Call, Judy Walton).

10. Develop therapeutic foster care programs.

MONTANA

Montana established a parent/professional group at the conference called Montana Families as Allies.

GOAL:

To develop a statewide network of local advocacy groups made up of parents and professionals organized by parents with professionals as a resource to provide:

1. support for parents and professionals and to provide information regarding services and systems;

2. provide a list of crisis advocates to help parents in crisis situations;

3. to generate group empowerment to influence systems and legislation.

Strategies (can do immediately):

What needs to be done and by whom:

1. Investigate and generate local community interest by distributing a handout to ED classes, group homes, agencies, State and private treatment centers and community mental health centers to inform parents about local meetings to be held in one month in each of five regions. (State coordinator: Dee Cranmer; Bozeman, Linda Webberson; Billings, Linda Christensen and Ruth Gunnarson; Helena, Dee Cranmer; Missoula, Denalie Bruins)

2. Use information gained at initial meeting to assess the interest level and goals of parents; establish organizational goals and time lines.

Strategies (long term):

1. Form regional advocacy groups;

2. Establish a newsletter;

3. Hold regional and State conferences;

4. Lobby NIMH/Governor's task force on behalf of ED for redistribution of Youth Services.

MONTANA (Continued)

RESOURCES:

1. PLUK/CASSP, investigate Montana Advocacy Program.

2. Eastern Montana University, investigate, through Linda Christensen, assistance with:

   a. contact/coordinate funding sources;
   b. assist with manpower/student power;
   c. assist with conference planing;
   d. help compile a resource directory;
   e. provide training in the areas of: assertiveness, coping/parenting skills; early intervention strategy.

NEVADA

GOAL:

Establish inter-agency communication (school, mental health, social services).

Strategies (can do immediately):

What needs to be done and by whom:

1. Write report of information with objectives provided through various groups/agencies. Share information with agencies and give goal sheets to administration (done by parents and individual delegates from Nevada).

2. Parents to share with administrators (done by CHANCE, mailing list) before May 10.

3. Create parent/professional partnership with continuity, communication/ involvement with the private sector.

4. Provide information through statewide agency mailing list (news release, state publications).

5. NACE conference session (done by member of NACE).

6. Mental health commission (NAMI).

7. Develop directory of resources and set up a computer network.

Strategies (long term):

What needs to be done and by whom:

1. Establish centeral information distribution with referral (develop "Warm-Line") (Volunteer parents and professionals).

2. Financial support, personnel.

3. Research.

4. Access already established services.

NEVADA (Continued)

Nevada Obstacles:

1. Statewide access and information referrals;
2. Determining obstacles between parent/professionals
   a. be able to separate issues, system versus individual;
   b. educate professionals.
3. Lack of cooperation and communication between mental health and schools.
4. Providing services for minority, low economic population:
   a. more minority awareness;
   b. offer services which are affordable.
5. Can't agree on definition of various disorders, criteria need for guidelines from state legislature.

NEW MEXICO

GOAL:

Establish a statewide informational network of parents and professionals the focus of which is to bring advocacy for seriously emotionally disturbed children to light.

Strategies:

What needs to be done and by whom:

1. Contact AMI, set up meeting with New Mexico AMI and this group, ask for representation and assistance (done by John De Paula).

2. All parents and professionals will recruit workers and contact local agencies (done by John, Santa Fe agencies; Sanda, Las Vegas; Gloria, Alberquerque agencies; Rebecca and Cornelia, Alberquerque groups, U & N parent training; Nancy, private psychological facilities).

3. Staff at one agency will be trained to work with parents and to train parents to work with parents (done by Gloria Roney).

4. Educate parents, re: rights, issues of anger (Rebecca, Cornelio).

5. Work with agency staffs (Gloria, Cornelio, Rebecca, Sandy).

6. Locate money to assist in the efforts, specifically for newsletter and conference.

7. By end of May will have meeting among ourselves to assess progress, plan on meeting with AMI for early June.

New Mexico Obstacles:

1. Professionals' and parents' goals are different.

2. Professionals fragmented.

3. Every agency doing something different.

4. Apathy among parents

   a. schools don't want to hear from parents;
   b. schools threatened by parents.

5. Stigma keeps people from becoming involved.

6. How to involve low income Hispanics and Indians.

NEW MEXICO (Continued)

Specific strategies:

1. Planning Parent-Professional conference, representatives from community, doctors, therapists, police, judicial.
2. Get media involved.
3. Invite Dominici.
4. Free up money through mental health for conference for network purposes.
5. Tagging up with AMI.
6. Parents and professionals need to be force, may not get top officials together.
7. Involve psychiatric hospitals.
8. Contact media to get work out.
9. Newsletter.
10. Parent training to get word out.
11. Contact agencies already involved with these special kids.
12. Door to door campaign to contact parents of BD kids.
13. 6 O'Clock News.
14. Make enough noise as one group to move the legislature, hook up with AMI or ARC.
15. Put power with families as opposed to already beleagured State.
16. CSP community.
17. Contact AMI to see what they are doing, their focus.
18. John will set up meeting with AMI to develop children's focus.
19. Contact parents reaching out.
20. Developmental disabilities planning council, source of possible funding.
21. Obtain 'how to mobilize parents' manual.

OREGON: Group 10

Strategies:

What needs to be done:

1. Locate other parents and volunteers

   a. find a meeting place, church, school, homes, etc.;
   b. form grassroots group;
   c. traditional and non-traditional organizations.

2. Goals formulated

   a. issues, group process;
   b. management issues.

3. Contact advocacy/self-help groups

   a. like ARC, how it started, cohesion;
   b. investigate/research;
   c. learn from their pitfalls.

4. Develop glossary with charts, titles, resource list with information.

5. Centralized information system.

6. Volunteer/paid advocates/consultant/lobbyist.

7. Self-help group members volunteer to go to IEP sessions with other parents.

Oregon Group 10 (Continued)

Obstacles:

1. Communication

   a. agency-agency;
   b. agency-parent;
   c. parent-parent;
   d. agency-funding source/policy makers;
   e. uses of power/language.

2. Public awareness

   a. needs of target population;
   b. uses of power.

3. Too few resources, fragmentation of services.

4. Inclusion of parents to service/treatment team, alienation.

5. Parent education/training, lack of

   a. opportunities;
   b. on-going training/informational support.

6. Parent frustration/anger.

7. Attitudes of treatment providers.

8. "Multihandicapped", limited resources.

OREGON: Group 11

GOAL:

To establish communication among families, service providers and policy makers to benefit families with emotionally disturbed children.

Strategies:

What needs to be done and by whom:

1. Access support for parents

   a. The Psychiatric Day Treatment Program at the U. of O. and the Morrison Center will call meetings of parents to discuss information and action from this conference. (Martha McCaw, Bruce Johnson)

   b. Those same agencies will elicit interest in single parent support groups. (Martha McCaw, Bruce Johnson)

   c. Take above information to OATS and other appropriate statewide organizations of service providers for emotionally disturbed children. (Mary Hoyt)

   d. The Mental Health Association of Oregon will work with parent support groups to develop coalitions to develop advocacy around needs, policy goals and legislative issues. (Muriel Goldman)

2. Create a pool of resources for information on emotional problems.

   a. Resurrect children's information line in the MED office of the MHD, through advocacy with the MED Advisory Council, with the MHAO acting as watchdog. (Mary Hoyt)

   b. Make available the phone number of the Metro chapter of the Mental Health Association, which has an information and referral service. (Muriel Goldman)

   c. Develop statewide MHAO number for information and referral. (Muriel Goldman)

   d. Develop parent handbook on Special Education in the Portland area. (Joseph Condon, Portland Public Schools)

OREGON Group 11 (Continued)

3. Improve interagency coordination to develop a larger pool of support services for families.

   a. Attend Oregon Agenda for the 1990's Conference in Portland, May 18-21. (All contact Oregon Council on Crime and Delinquency)

   b. Take information back to represented agencies and discuss ways to implement this objective. (All)

   c. Advocate for systems improvement and interagency communication and coordination. (Muriel Goldman, MHAO, all)

Oregon Group 11 Obstacles:

1. Lack of parent support systems.

2. Lack of parents as advocates.

3. Lack of communication between professionals, parents, policy makers.

OREGON: Group 12

GOAL:

Form a statewide organization on SED kids for parents/kids/professionals.

Purposes:

- o Put out a directory of services
- o Develop a newsletter
- o Provide training for parents and professionals
- o Regional conferences for parents and professionals
- o Legislative action

Strategies:

What needs to be done:

1. Form a support group in Grants Pass.
2. Form a support group in Monmouth.
3. Form a parent group at OHSU, child psychology.
4. Contact Oregon AMI president.
5. Oregon Ed Division will provide support for school problems, call Howard Smith or Kim Kay.
6. COPE will provide information of PL 197-48 and how to develop local support groups.
7. Ask MHD to provide staff.
8. Contact Oregon Bar Association about their special seminars for handicapped.
9. R&T Center will mail follow up letter to group.

OREGON Group 12 (Continued)

Obstacles:

1. Parents lack power.
2. Parents lack knowledge.
3. Lack of options in schools and community.
4. Need for parent groups to force change.
5. Reprioritize funds, look for new funds.
6. Need state level advocacy group.
7. Need better planning, coordination and organization at State level.
8. Parents need a typed report of evaluation done on their kids.

UTAH:

GOALS:

1. Gain cooperation between educational system and social services and mental health systems.
2. Gain communication between parents and professionals.

Strategies (can do immediately):

What needs to be done:

1. Meet May 8th, Utah Parent Center, parent groups, professionals, Chris Walther (Wanda Pillow will do this).

Strategies (longer term):

What needs to be done:

1. Place parents on carousel committee of state representatives, educational representatives.
2. Educate parents/professionals, get involved in PTA.
3. Organize statewide referral source through Utah Parent Center.
4. Meet again to organize presentation at state level committee.

Utah Obstacles:

1. Lack of cooperation between education and social services.
2. Lack of respect for parents
3. Lack of central referral source.
4. Lack of effective lobbying.

WASHINGTON

GOAL:

Networking, information sharing, support and information between parents and professionals; professional self-assessment on efficiency, effectiveness and objectivity.

Strategies:

What needs to be done and by whom:

1. Conduct a national/state needs assessment.
2. Take advantage of the new money available through CASSP to assist collaboration between parents and professionals.
3. Support and information groups for parents and professionals.
4. Work to break the myth that parents (some) share, which labels professionals as uncaring. How?
5. Networking, information sharing with Washington.
6. Have DSHS publish a statewide policy which designates someone in charge of information and referral for parents and professionals.
7. Utilize public schools as a resource to provide information and support to parents and professionals.
8. Social Workers learn to refer clients to other knowledgeable individuals/systems when they get stuck are no longer effective. From the outset tell parents do not have all the ansewrs and not to be afraid to try someone else.
9. Form parental support groups, specifically to address abuse (verbal and physical) issues which occur in the school system.
10. Professional self-assessment in any social service delivery system.
11. Pull group together in Fall (Stan Rose).
12. Contact higher education to discuss statewide conference (Jan Hopler).
13. Ensure parent involvement on coordinating council and needs assessment for CASSP grant.
14. Foster Parent Association develop directory of parent support groups in state.
15. Start father's support group (Stan Rose).

WASHINGTON (Continued)

Other issues that arose in Washington groups:

1. Are there different agendas from those in this room?

2. Do we want to network as a group? Information sharing and contracting each other in the future.

3. Explanation of CASSP grant, what are its impacts for the future? Who will influence the disbursement of CASSP funds? What will be the parental involvement?

4. Parental concern: need appropriate treatment and explanations of what is happening to our children, deemphasize drug and alcohol emphasis and recognize these kid's problems for what they really are.

5. Parents need support, education, joint parent-professional groups.

6. Who is in charge here? We need to answer this. DSH should clarify this. Due process clarified.

   School staff and parents should be educated together at joint conferences so that we have the same information about special ed children's needs and problems.

7. Partnership cut across geographic and agency problems.

8. Parent training programs, parents need to train other parents in regards to their experiences, share knowledge. Should be gathered at the school level. Parent-parent often more effective than social worker-parent relationship.

9. We need to meet again.

10. Professionals need to:

    a. Look at one's self first, continuous process.

    b. Sit down with parent and say "I don't know", and then call some other professional for help.

Washington Obstacles:

1. Being able to accurately identify the exact number and needs for emotionally troubled kids (i.e. to get adequate services through the legislative process.

2. Having to relate ET kids as CMIs to get money for services. Also, labeling them drug and/or alcohol addicts. Expand legal definitions.

3. Foster parents only get $238/month to raise a pre-adolescent

WYOMING:

GOAL:

To organize advocacy and support network for parents of special needs children.

Strategies: (can do immediately)

What needs to be done and by whom:

1. Contact key people in community systems, schools, mental health, physicians, private practitioners, (done by all 2 delegates from Wyoming).
2. Identify parents (all 2 of them).
3. Focus on Cheyenne.
4. Identify system advocates.

Strategies: (longer term)

What needs to done and by whom:

1. CASSP Grant, meet with MH and have them apply.
2. Organize Alliance with representatives from special ed from school system, mental health, youth alt, DPASS and parent representations, DDP&A.

Wyoming Obstacles:

1. No organized advocacy groups.
2. Rural community with minimum treatment resources.

SUMMARY

As these conference materials demonstrate, the Families as Allies Conference took some giant steps toward successfully addressing its primary objectives. The keynote speaker's theme of mutual respect helped set the tone for parent-professional collaboration and for much of the work that occurred during the rest of the conference. Subsequent speakers, panelists, and workshop leaders provided conference participants with both thought-provoking commentary and with ideas which they could adapt to their own circumstances.

OBSTACLES TO PARENT-PROFESSIONAL COLLABORATION

Obstacles to parent-professional collaboration were explored. Theories of etiology of mental illness often unwittingly cast parents as villains and are a serious obstacle to parent-professional collaboration. These beliefs lead to professionals blaming parents, holding them responsible and viewing them as pathogenic agents. Similarly, parents often also believe they are to blame for their children's problems. This belief may lead to guilt, shame, fear and avoidance of mental health professionals, teachers and others.

Professionals tend to view children's needs and problems from within the context and capacities of the agency in which they are employed and within a relatively short time frame. Parents, on the other hand, have an ability to see the many needs of the child and the family, and thus the need for a wide range of services over a longer time span. Parents, however, may lack the knowledge and skills to pull together a long term comprehensive plan unassisted.

Professionals and parents are further constrained by the requirement that professionals operate within agency policy and within the limitations imposed by funding sources. Agency policies and funding requirements are often impediments to the delivery of appropriate services to emotionally handicapped children.

OVERCOMING THE BARRIERS TO PARENT-PROFESSIONAL COLLABORATION

The second day of the conference was devoted to developing strategies to overcome barriers to parent-professional collaboration. Most participants agreed that the single most important action which may be undertaken to improve parent-professional relations requires professionals to adopt a new attitude towards parents which views them as equals. The relationship between parents and professionals may take several forms, and may be described in terms of the parents' role: (a) as patients, with some problem or disorder in need of treatment; (b) as allies, or partners who can contribute information, energy and perspective to a cooperative effort with professionals on behalf of children. Although each of these roles may be appropriate for parents, the relationship between parents and professionals is most likely to experience the greatest improvement when parents are viewed as allies or partners. All parties benefit if parents and professionals share a common concern and mutual responsibility for the well-being of their emotionally handicapped children and youth.

CONFERENCE OUTCOMES

State delegations generated action plans and strategies for implementation upon returning to their home states. Planned activities include efforts to better coordinate the activities of existing statewide advocacy groups, commitments to establish parent support groups in specific cities or regions, development of resource directories, establishment of parents-training-parents capabilities,

development of parent handbooks, publishing newsletters, and engaging in legislative advocacy. Hawaii and Colorado plan to replicate the Families as Allies Conference within their respective states. The states of Idaho, Montana and New Mexico also plan to hold conferences designed to promote parent-professional collaboration. A Families as Allies Conference for the Southeastern United States has been funded by CASSP (Child and Adolescent Service System Program) monies and will be held in 1987.

Locally, one Oregon agency conducted a "follow-up conference" for parents and staff seven days after the Families as Allies Conference in an effort to establish an advocacy group for emotionally handicapped children. A core group of parents were identified who plan to meet frequently and reach out to other families in the community with seriously emotionally handicapped children.

One parent wrote to the Center and advised that, as a direct result of the conference, she: (1) made an appointment to meet with school personnel to discuss her child's special needs; (2) obtained the services of a parent advocate to assist in her meeting with school authorities; (3) talked to a number of people about the conference as a first step in organizing a parents' group; (4) started a journal; (5) wrote to six organizations for information, and (6) began to assemble a file of reference materials on services for seriously emotionally handicapped children. All of these accomplishments occurred during the first week following the conference.

CONCLUSION

The ripple effect of the conference is just beginning. The conference provided new insights for both professionals and parents. Each gained an understanding of the difficulties and constraints affecting the other. Both parents and professionals affirmed their common interest in providing the best possible services and environment for emotionally disturbed children and adolescents. The conference stimulated individual parent and professional activities as well as provided the impetus for planning activities at the agency, community and state levels.

These conference proceedings may be useful to others planning to organize similar conferences designed to promote parent-professional collaboration. Staff members of the FAA project are available to provide assistance in planning and implementing parent-professional collaboration. For those interested in promoting a similar conference, we can provide budgeting suggestions, information on conference site requirements and post-conference follow-up activities. Additionally, we have written suggestions for conference facilitators, scholarship application forms, and reimbursement forms which we would be happy to share.

This conference was a gratifying experience for Research and Training Center staff; we urge others interested in parent-professional collaboration to explore ways to bring these two groups together. Within a forum which encourages open and frank dialogue, parents and professionals can form alliances on behalf of the children and adolescents who constitute our common concern.

SUMMARY

FAMILIES AS ALLIES

CONFERENCE EVALUATION FORM

April 28 & 29, 1986
Portland, Oregon

Please check:

Parent__(N=27)____ Professional__(N=48)__

1. Overall, I thought the conference was: (circle one)

	5 Excellent		4		3 Average		2		1 Poor		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%
PARENTS:	14	(51.8)	13	(48.2)	0	(0.0)	0	(0.0)	0	(0.0)	27	(100)
PROFES-SIONALS:	19	(39.5)	24	(50.0)	4	(8.3)	0	(0.0)	1	(2.1)	48	(100)

2. In the future I expect the information and experience I gained here to be: (circle one)

	5 Very useful		4		3 Somewhat useful		2		1 Not useful		TOTAL	
	N	%	N	%	N	%	N	%	N	%	N	%
PARENTS:	19	(70.4)	7	(25.9)	1	(3.7)	0	(0.0)	0	(0.0)	27	(100)
PROFES-SIONALS:	17	(35.4)	20	(41.6)	9	(18.8)	1	(2.1)	1	(2.1)	48	(100)

FAMILIES AS ALLIES
April 28 and 29, 1986
Portland, Oregon

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